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Many hops, many stops: Care-seeking 'loops' for diabetes and hypertension in three urban informal settlements in the Mumbai Metropolitan Region

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Abstract

Background: The rising burden of Non-Communicable Diseases (NCDs) in urban informal settlements poses a serious threat to health equity. In recognition, there has been interest in fine-tuning policies on NCDs to meet the unique needs of people living in such settlements. To inform such policy efforts, we studied the care-seeking journeys of people living in urban informal settlements for two NCDs- diabetes and hypertension. The study was done in the Mumbai Metropolitan Region, India.

Methods: This qualitative study was based on interviews with patients having diabetes and hypertension, supplemented by interactions with the general community, private doctors, and public sector staff in the area. We conducted 34 in-depth interviews, 13 short interviews and 6 Focus Group Discussions. We synthesized data thematically and used the qualitative software NVivo Version 10.3 to aid the process. In this paper, we report on themes that we, as a team, interpreted as striking and policy-relevant features of peoples' journeys.

Results: Care-seeking pathways for diabetes and hypertension were often convoluted, with delays in diagnosis and treatment initiation. Most people's first point of contact for medical care were local physicians with a non-allopathic degree, who weren't always able to diagnose the two NCDs. One of the most striking features of the journey was the multitude of healthcare providers sought by people- both from the private and public sectors. People's stories comprised multiple points of diagnosis, re-diagnosis, treatment initiation, and treatment adjustments. Advice from neighbours, friends, and family played an essential role in shaping the care-seeking process. Trade-offs between saving costs and obtaining relief were being made constantly.

Conclusions: Our paper attempts to bring the voices of people to the forefront of policies on NCDs. People's convoluted journeys with numerous switches between providers indicate the need for reliable 'first-contact' points for NCD care and integrating care across healthcare providers- two critical features of good primary-level care. It is important to educate the public on NCD prevention, early diagnosis, screening, and treatment compliance. Health policies should strive to make journeys less messy for patients, rather than assume that care-seeking events linearly unfold from awareness to diagnosis and treatment.

1. Introduction

Recently, urban informal settlements across Low and Middle-Income Countries (LMICs) have noted an increase in the burden of Non-Communicable Diseases (NCDs) (1, 2, 3). Evidence suggests that residents of such settlements are at increased risk for NCDs due to a range of factors, including chronic stress, unfavorable working conditions, poor diets, and environmental pollution (4, 5, 6). Furthermore, access to high-quality healthcare is frequently lacking in such areas (7, 8). The adverse influence of financial insecurity and social marginalization, added to all of this (9,10), further compromises NCD outcomes in this population group.

As a consequence, there is interest across LMICs in aligning and fine-tuning health policies to respond to the increasing NCD burden in urban informal settlements. One compelling way to aid such policy endeavors is through empirical understandings of people's care-seeking journeys for NCDs in these spaces. A care-seeking journey is characterized as a sequence of actions that begins with awareness about something not being right; thereafter, intervention from formal and informal health resources is sought (11). Examining care-seeking journeys can enable contextualized understandings of people's physical and emotional experiences and, thereby, help include community voices in policy discussions (12, 13, 14). Studies of such journeys in the past have provided policy evidence for strengthening diagnostic processes, tweaking treatment regimens, and reducing delays in the care-seeking process (15, 16). Overall, such inquiries have served as important tools for making health policies more people-centered (17). Indeed, the recent 'intent to action' series by the World Health Organization treats the lived experiences of patients as key evidence for improving NCD policies (18).

This study aims to get deeper insights into the care-seeking journeys of people with diabetes and hypertension. The study was done in three informal settlements in the peripheral areas of the Mumbai Metropolitan Region in India. The two NCDs- diabetes and hypertension- were chosen since a high prevalence of these diseases has been reported in from urban informal settlements in India (19, 20).

This qualitative study adds to existing evidence on care-seeking journeys for NCDs in LMICs. Studies of this kind are increasingly being recognized as important evidence for fine-tuning health policies. Earlier studies on this topic have highlighted issues of delayed diagnosis and lack of continuity in NCD care- owing to poor quality primary healthcare systems, cost concerns, and a lack of clarity over where to seek care, inter alia (12, 16, 21). We add to this literature a case study that considers the unique features of the urban informal settlements contexts, such as the existence of a mixed (public and private) health system and the resource constraints faced by the urban poor in accessing care.

Indian context: The burden of NCDs is rapidly rising in India (22, 23). Whereas NCDs were earlier perceived as 'diseases of the rich' only (1), current evidence suggests that the urban poor are also vulnerable to this set of diseases (24, 25).

The urban public health system, particularly at primary levels, is underdeveloped in most places in the country (26, 27). Also, the public health sector has conventionally focussed on providing select services for maternal and child health and certain priority diseases only. Though a national program to combat NCDs has existed for many years, the intent to integrate NCD care comprehensively into all tiers of the public health system has only recently gained political priority. Presently, policies in India strongly advocate for including screening, treatment, and management of NCDs through the public health system (28, 29). However, the addition of NCD care appears to put even more pressure on the nation's already overburdened and under-resourced public health system (30).

Recent evidence suggests that people in urban informal settlements often pay out of pocket and consult local private healthcare providers for the diagnosis and treatment of NCDs (31, 32). This evidence seems to be consistent with this population's general care-seeking trends for minor acute ailments (33, 34). However, the care pathway for NCDs is likely to differ greatly from care for minor acute ailments since it involves long-term treatment costs, lifestyle changes, and follow-up. At present, the care-seeking pathways for NCDs are less understood, particularly from the perspective of communities living in urban informal settlements in India.

2. Methods

2.1 Case setting

This study was done in a peripheral Municipal Corporation (urban geographical region under a local governing body) in the Mumbai Metropolitan Region, Maharashtra, India. This corporation has a population of 0.7 million, of which 44% live in informal settlements. The density of people per square kilometer is 26871 (35). Historically, these settlements grew around a textile industry hub. Hence, many of these settlements are home to migrants who work in the loom industry. The area has access to a mix of public and private healthcare providers. One public secondary-level hospital (100 beds) serves as a referral unit for 15 primary-level facilities operating under this Municipality.

2.2 Study design

This is a cross-sectional, qualitative study. The data mainly comprises interviews with patients with diabetes or hypertension (or both) who shared their care-seeking journeys with us based on their memories. These interviews were supplemented with information from community-level group discussions, visits to the public secondary-level hospital and one primary-level facility in the area, and interviews with local private healthcare providers. The supplementary information we collected enabled us to understand the care-seeking journeys of patients from a broader perspective that acknowledged the context of healthcare provision in this area. The main topics discussed during our interactions are summarised in Table 1.

Table 1: Themes covered during our interactions

Diabetes and hypertension patients (interviews)	**Community members (Focus group discussions)**	**Healthcare providers (public and private) (interviews)**
Story of the patient's care seeking journey Probes: -Awareness of the disease(s) -Symptoms, severity, complications -Point of screening and diagnosis -Treatment and Adherence- medicines, diet, cost of treatment, reasons for poor adherence -Access to healthcare- public and private health providers, relations with healthcare providers, regularity of follow-up	-Perception of the severity of diabetes and hypertension -Awareness of the preventive measures, diagnosis, screening, treatment -Perception and access of public and private healthcare	-Awareness about diabetes and hypertension -Nature of care provided and experiences of treating patients for the two diseases - Challenges faced in the provision of care

2.3 Participant selection and recruitment

This study was conducted in the field areas of the Society for Nutrition, Education and Health Action (SNEHA), a nongovernmental organization that has been working in urban informal settlements in Mumbai since 1999. SNEHA has a long-standing relationship with the community in the study area. The field staff of SNEHA initially identified patients, community members, and doctors. They explained to them the purpose of the study and inquired about their willingness to participate. The researchers from SNEHA thereafter conducted the interviews and discussions as per the participants' convenience after a formal process of informed consent. We purposively sampled for diversity in age and gender (all study participants), migration status (for all community participants), and years of diagnosis/treatment of the disease (for only patients).

2.4 Data collection

Data collection was done from September to December 2022. A total of 34 in-depth interviews (IDIs), 13 short interviews, and 6 Focus Group Discussions (FGDs) were conducted (see Table 2).

Table 2: Details of study participants

Participants	Patients of diabetes and hypertension					Community	Private doctors	Public health staff
Methods of data collection	*In-depth interviews (26)*				*Short interviews (public hospital) (8)* *	*Focus Group Discussion (6)*	*In-depth interviews(8)*	*Short interviews(5)* *
	Diabetes	Hypertension	Both	Total				
Total number of participants (87)	10	9	7	26	8	40	8	5
Age (years)								
<35	1	0	0	1		27	-	-
35-50	4	2	1	7		10	-	-
51-65	4	4	6	14		3	-	-
>65	1	3	0	4		0	-	-
Gender								
Male	4	7	2	13		13	7	2
Female	6	2	5	13		27	1	3
Years of Residence in the community								
<10	2	1	0	3		13	0	-
10 to 20	2	4	0	6		15	4	-
>20	6	4	7	17		12	4	-
Employment								
Employed	5	5	2	12		21	8	5
Unemployed/Retired	5	4	5	14		19	0	0

***** *These interviews were short since these were meant to provide only supplementary information about NCD care in the public hospital.*

The participants' preferred local languages, Hindi and Marathi, were used. Authors MB, JS, and SR conducted the interactions; all three are well-trained in qualitative data collection methods and familiar with the local context. On average, the IDIs and FGDs lasted 20–30 minutes. The interviews with patients were conducted in their homes, those with healthcare professionals were conducted in their workplaces, and the focus group discussions (FGDs) were held in anganwadis (local government playschools) or one of the participants' homes.

2.5 Data analysis

All interactions with community members and patients (except the eight short exit interviews at the hospital) were recorded. Of the eight interviews with private providers, five were recorded; and of the five interviews with public health staff, three were recorded (as per the participants' preferences). These recordings were transcribed into English for further analysis. For the non-recorded interviews, we took detailed field notes. As is typical of qualitative studies, data analysis processes were initiated simultaneously with data collection (36).

We followed the steps that Miles and Huberman recommend for the analysis of data, starting with data reduction (initial condensing), then working with data displays (compressed assemblies of information), and finally, drawing meaningful interpretations (37). We had data debriefing sessions after every data collection visit to discuss emerging learnings. Ideas from the transcripts were also discussed in a team to arrive at a standard set of codes. The transcripts and field notes were sorted and coded using the qualitative software NVivo Version 10.3.

2.6 The analytical framework used

To choose an analytical framework for our study, we examined existing literature on patient journeys for NCDs. We found that many papers used clinical headings- such as diagnosis, initiation of treatment, follow up and management of the disease- to explicate the patient journey (11, 38, 39, 40). For example, a recent review of NCDs in LMICs used the term ‘touchpoints’ (awareness, screening, diagnosis, treatment, and adherence) to describe the patient journey through the health system (11). Other articles have also noted the importance of examining patient journeys through a "continuum of care" approach as care-seeking for NCDs should ideally involve multiple follow-ups with repeated points of contact with the health system (41, 42).

These ideas informed the initial tools of our study. We also based our preliminary analysis on the different ‘touchpoints’ we encountered in patient stories. But this analysis revealed that some of the unique findings in our context did not fit into the existing frameworks very well. For instance, patient journeys in our study appeared to be highly convoluted. Further, given the existence of a mixed (public and private) and pluralistic (allopathic and alternate medicine) healthcare system in India (43), there was constant ‘hopping’ between different providers for NCD care. These issues were not being captured through existing NCD care-seeking frameworks. Thus, in our paper, we have built further on existing ideas and attempted to develop a “grounded” framework (44) to better represent that chaotic situation of care-seeking on the ground. Since this framework evolved iteratively from our data, we have discussed it at the end of the paper (see Figure 1).

2.7 Ethical Considerations

Ethical approval for the research was obtained from Sigma Research and Consulting Pvt. Ltd. on 28th September 2022. Informed consent was verbally obtained from all participants. In cases where the participant granted permission to audio record the interviews, the consent and ensuing interactions were recorded on a smartphone device. In some cases, where the participants did not agree to audio recording, non-recorded verbal consent was obtained, and field notes were taken during and after the interaction. Permissions were obtained from the municipal ward corporator responsible for the population under study and relevant public health system authorities in the area.

3. Findings

People recounted having long and convoluted care-seeking journeys for the two NCDs we studied. These journeys often involved multiple ‘hops’ between different kinds of providers, as well as experimentation with different types of treatment regimens. In most of the stories we heard, the diagnosis of the two NCDs was delayed until people’s life routines were extensively disrupted due to worsening symptoms. Further, few people spoke of routine follow-ups. In this section, we have described some of the salient features of people's care-seeking journeys that our team interpreted as noteworthy.

3.1 Initial complaints and the first providers sought

Many patients began their stories by talking about symptoms that interfered with their lives. These symptoms often included headaches, body pain, anxiety, dizziness, and tiredness. Since patients' early memories were hazy, it was challenging to determine how long these symptoms had manifested in people's lives prior to a formal diagnosis. Most patients said that they dealt with these early, not-very-serious symptoms by going to a nearby source of healthcare, such as a pharmacy (drugstore) for over-the-counter drugs and visiting a local private doctor referred to as a 'small' doctor:

"His clinic is not big but has been there for many years. All members of our family get medicine only from him. On this road, he is a famous doctor. He himself gives the medicine. He takes only fifty rupees." (Female, 32 years, diagnosed with diabetes six months prior to the interaction)

"Over time when I started feeling uneasy, I went to my family doctor. He said my BP (blood pressure) was high, so he gave me a pill to keep it on my tongue. He also asked me to visit a big doctor". (Male, 52 years, diagnosed with hypertension eight years prior to the interaction)

Small doctors typically had small-sized, private clinics within the narrow lanes of the informal settlements, and they were easily accessible to people. Mostly, these doctors had degrees or diplomas in alternate systems of medicine like Ayurveda, Unani, and Homeopathy, but they also prescribed basic allopathic drugs.

This beginning of the care pathway from the small doctors appears to be common for most minor health complaints. Patients shared that small doctors spoke kindly, often provided 'small' medicines during the consultation, and, importantly, charged fees that they could afford. These fees were typically only a fraction of the fee charged by an urban allopathic doctor (Allopathic doctors charged 500 to 1000 Indian National Rupees (INR) and in contrast, these doctors took a fee of 50 to 100 INR). The small doctors also shared that they occasionally accommodated patients' requests by deferring taking fees for consultation until the patients could afford to pay them.

Small doctors also admitted that they usually provided only symptomatic treatment:

"If someone feels uneasy, I give them medicine to help them relax. I make them lie down with their legs up, and I make them chew on ginger. Because of this, the heaviness in their chest and lack of oxygen starts recovering." (Small doctor, clinical practice for twenty-five years)

These doctors preferred to refer patients to more qualified doctors for the formal diagnosis and continued treatment of NCDs. Long-term treatment for NCDs was perceived as costly. One doctor also noted that recommending such long-term, costly treatment regimens to patients would undermine his reputation as a reasonably-priced doctor and have a negative impact on his practise. Less than one-fourth of the patients we interviewed had been diagnosed by the small doctors. The limited role played by these doctors, often the first points of healthcare contact, clearly speaks to a missed opportunity for the screening and early diagnosis of NCDs.

3.2 The subsequent journey involved many 'hops' between different kinds of providers

When the symptoms experienced by patients were not controlled as anticipated, people did one or more of the following. They either returned to the small doctors with more extensive complaints or reached out to 'big' private doctors. 'Big' private doctors usually possessed at least an undergraduate degree in allopathic medicine, and their workspaces were outside the informal settlements and sometimes even in adjoining cities. Less often, people reported seeking care from the public sector and non-profit hospitals.

Table 3: Healthcare providers sought by patients in our study

Patient number	Sex	Age	Disease	Duration of the disease	Healthcare providers sought									Reasons for switching between healthcare providers
					1	2	3	4	5	6	7	8	9	
1	F	50	D, H	5 years	🟧 ✓	🟧	🟧	🟩	🟧					Confirmation of diagnosis and no relief
2	F	57	D, H	5 years- H 1 year-D	🟦 ✓	🟦								Separate doctor sought for hypertension and diabetes
3	F	40	D, H	1 year	🟪	🟧 ✓	🟧							No relief

4	F	32	D	6 months	⬛ ✓									No switch, has stopped medicine due to high cost
5	M	55	D	6 months	🟫	🟫 ✓								No relief
6	F	45	D	6 months	🟫 ✓									Confirmation of diagnosis before starting medicines
7	M	67	H	2 years	🟫 ✓									No switch
8	F	45	D	15 years	🟧 ✓	🟫	🟦	▦	🟪					Finances, migration, low access to medicines
9	F	65	D, H	8 years	⬛	🟫 ✓	🟫	🟫						No relief and for treatment of co-morbidities, specialist care`
10	F	50	D	12 years	🟫 ✓	🟫	🟩	▧	🟦					Cost of medicines, medicine did not suit, treatment of co-morbidities
11	F	40	H	3 years	🟫 ✓	🟫								No relief
12	F	55	D	1 year	⬛ ✓	▧	🟦	▦	🟪					No relief and high cost of medicine
13	M	75	D	>12 years	🟫 ✓	🟫	🟫	🟨						Relief, for treatment of co-morbidities
14	M	55	H	4 years	⬛ ✓	🟫								No relief
15	M	53	D	5 years	⬛ ✓	🟫	⬛	⬛	▨	🟫	🟪			No relief and treatment of co-morbidities
16	M	86	H	12 years	🟧 ✓	🟧	⬛							Migration
17	M	65	D	2 years	⬛	⬛	🟫 ✓	🟩	⬛					No relief
18	M	62	D, H	2 years	🟫	🟫 ✓	🟫							For treatment of complications of diabetes
19	F	60	D, H	2 years	🟫 ✓	⬛	🟫	▤	🟪	🟩				No relief, high cost of treatment, treatment of co-morbidities
20	F	35	D	7 years	🟫 ✓	🟫	🟫	🟦	⬛	🟪				Switched from obstetrician to general physician, cost of treatment
21	M	56	H	6 years	🟫	🟫	🟫 ✓	▦	🟫					No relief and treatment of co-morbidities
22	M	55	D,H	4 years	▧ ✓	⬛	🟫	🟦	🟫	🟧	🟪			Treatment of co-morbidities and due to the high cost of treatment
23	F	45	H	16 years	🟫 ✓	⬛	🟫	⬛	🟫	⬛	🟪			Migration, high cost of medicine s
24	M	63	H	1 year	🟫 ✓	🟫	🟦	▧	⬛	🟧	🟫	▧	🟪	Cost of treatment and medicines and treatment of co-morbidities
25	M	66	H	4 years	🟫 ✓	🟫	🟨							High cost of treatment
26	M	52	H	8 years	⬛ ✓	🟫	🟫	▧						Better care and high cost of treatment

▩ Small local private doctors	🟦 Public hospital in the area studied	🟩 Traditional medicine providers
🟫 Big private doctors hospitals in the area	▧	🟪 Private pharmacies/chemist

The care-seeking illustrated in the table focusses on the point of diagnoses and the number of provider switches made after this point. We haven't tabulated mentions of their early visits to small providers because most people could not recall the exact numbers of visits and switches made between doctors before their diagnosis.

🟧
🟧 Big private doctors/hospitals in nearby cities
🟦 Public hospitals in nearby cities
🟨 Trust hospitals
🟪
✓ Point of diagnosis

Table legend:

D- Diabetes M- Male
H- Hypertension F- Female

One of the most striking features of this part of the care-seeking journey was the multitude of providers sought by people. Table 3 notes the number of providers sought by each patient we spoke to. We found that most patients switched providers multiple times, including hopping between 'small' and 'big' doctors, the public and private sectors (profit and non-profit), and the allopathic and alternate medicine sectors. We found only three patients who recalled visiting only one doctor as part of this journey (and two of these three patients reported being diagnosed only six months prior to our interaction with them).

People reported switching providers for multiple reasons, including the confirmation of diagnoses; no improvement in symptoms; in search of better-suited treatment; due to co-morbidities; to avoid the high cost of consultations that people could not afford at certain points in time; and based on the assortment of advice they received from well-wishers on the varied expertise of different healthcare providers.

The reasons shared by people for switching doctors signal the lack of a clear-cut pathway for accessing NCD care. To begin with, the familiar circle of local 'small' doctors, whom people were usually accustomed to, comfortable with, and could easily access, could often not diagnose or treat NCDs in this setting. Thus, people had to explore a previously unexplored set of providers—the 'big' private doctors—who were more qualified but, at the same time, costlier. Patients often expressed feeling powerless in the face of the high costs they incurred at the 'big' private clinics. They also felt uneasy asking the 'big' doctors (who were perceived as very busy) for advice and questioned the legitimacy of the tests prescribed by these doctors. This lack of trust also contributed to extensive experimentation with different kinds of providers and diverse treatment regimes. Advice from well-wishers (family and friends) and 'try and see' attitudes appeared to guide the entire care-seeking journey. The two cases in Table 4 illustrate some of these points.

Table 4: Excerpts from patient stories to illustrate 'hopping' between providers

Excerpt from Rani's story *Rani was diagnosed with diabetes during her routine antenatal check-ups in a 'big' private hospital. She continued taking her diabetes medication up until after her pregnancy, at which point she quit. When she felt unwell again, she went to another private doctor, whose medicines she found to be too expensive to buy on a long-term basis. So, she went to the public hospital (at a distance of 5 kilometers) for free medicine. But after a few months, she found it challenging to go repeatedly to the public hospital for medicine refills due to child-care responsibilities. Hence, she stopped going there. At the time of the interview, she reported going to a small private doctor for check-ups and medicine. But she also added that sometimes she skipped the check-up and took the medicines directly from the local pharmacy.* ***(Name changed, female, 35 years, diagnosed with diabetes 16 years prior to the interaction)***
Excerpt from Abdul's story *Abdul had a boil on his back, which did not heal for a few days, following which he visited a 'big' private doctor, who diagnosed and prescribed medicines for diabetes. When he got typhoid, he went to another doctor for treatment; this doctor changed the diabetes medicine due to his complaints about body itching. But he found this doctor to be rude and expensive, and hence, he never went to him again. At present, he continues the diabetes medicines given to him earlier without follow-up. He sometimes gets his sugar tested on his own and consults yet another small doctor in case of any abnormalities in the results.* ***(Name changed, Male, 53 years, diagnosed with diabetes five years prior to the interaction)***
Excerpt from Lakshya's story *During the COVID-19 lockdown two years ago, Lakshya had trouble breathing. Her family brought her to a nearby camp to undergo testing which didn't help. She was admitted to a private hospital as her condition worsened, and following a battery of tests, she was diagnosed with diabetes and hypertension. After her diagnoses, she visited a local private doctor, who gave her diabetic medication. This medicine did not suit her. So, she went to another big private doctor and received a different prescription from him. She only takes diabetes medicine since she can't afford to take hypertension medication. Six months into her diagnosis, she went to get retested in a free camp organized by a private hospital in an adjoining city, where an angiography and several other tests were done. From this hospital, she received new prescriptions for medication for diabetes and hypertension, and for asthma (diagnosed newly). She also takes medicine from the pharmacy*

directly as needed, and ayurvedic drugs from a traditional healer. ***(Named changed, Female, 60 years, diagnosed with diabetes and hypertension two years prior to the interaction)***

3.3 The care-seeking journey was cyclic, with multiple diagnoses and treatment points

We found that people did not move from awareness to diagnosis and further from diagnosis to treatment in a linear manner. People's stories often comprised multiple points of diagnosis and re-diagnosis; and multiple points of treatment initiation, adjustment, stopping, and re-initiation. Since these points were often cyclically encountered, we have described these points in terms of two ‘loops’ in the care-seeking journey: the diagnostic loops and the disease management loops.

3.3.1 The diagnostic loops

Around three-fourths of the patients we interviewed reported that their diagnosis was done at the ‘big’ private doctor (see Table 3, which marks the point of first diagnosis). However, this diagnosis did not immediately or always lead to effective treatment and management. This was because some patients ignored the early diagnosis, only to be re-diagnosed subsequently after the symptoms worsened. Some went to a range of doctors to confirm their diagnosis before believing it. For instance, one woman who was diagnosed with diabetes by a skin specialist found it hard to see the connection between diabetes and her skin problems, and struggled to believe her diagnosis:

"I had a cut that did not heal and became painful. I went to a private skin doctor, who diagnosed me with diabetes. But my family was worried and asked me to confirm. I went to another doctor to confirm, and there it also showed up. I went to five doctors in total. When they all told me I have sugar (diabetes), that is when I believed it." (Female, 60 years, diagnosed with diabetes five years prior to the interaction)

Some others got diagnosed, initiated, and then stopped treatment and subsequently had to be re-diagnosed. Additionally, the re-diagnosis was frequently carried out by various healthcare professionals who weren't necessarily aware of the patient's history.

Two departures from this typical diagnosis pathway were observed. One departure happened when the diagnosis happened incidentally. We spoke to five patients who had gone to the hospital for other reasons (such as for a COVID-19 test or vaccination or a pregnancy check-up) and had found out incidentally that they had diabetes or hypertension. The second happened when the diagnosis happened very late, during emergencies when the patients were admitted to a hospital, often with a stroke or a heart attack.

"I had a heart attack, and I went from one private hospital to another before finally going to a public hospital in Mumbai. There, they did my angioplasty... At that time, I found out that I had hypertension." (Male, 63 years, diagnosed with hypertension two years prior to the interaction).

Of the two conditions, in the stories we heard, hypertension showed this pathway of detection more often, having an insidious onset with less severe symptoms during the early stages. However, for both diseases, the stories shared by patients suggest routine screening might have allowed for earlier diagnosis.

3.3.2 The many loops in the management of diabetes and hypertension

We found several variations in the ways that patients worked with their treatment regimens. They sometimes completely stopped all medicines; or adjusted dosages on their own; or took partial medicines; or reserved costlier allopathic medicines only for emergencies while opting for home remedies and alternative medicine on a routine basis. In many stories, people reported taking medication in a cyclic manner. That is, they stopped when they felt better or had financial constraints; and restarted when the symptoms emerged again. Fatima’s case below is an illustrative example of how people adjusted their medicine cyclically.

Fatima lived in a modest one-room house with her family. She had a bedridden husband and a daughter who was mentally challenged. Her son earns, and she supplements his income by pearl-beading necklaces. Upon being diagnosed with diabetes, she took medicines from a private doctor (who charged her reduced fees). Fatima took these medicines for some time, but when she started feeling better, she stopped taking them to save money. After a few months, her symptoms reappeared. She again went to the doctor, who requested that she continue the medicine. However, the cost of medicine was too high for her. So, she went to the public hospital for free medicines on the advice of a neighbour. But she felt the medicines given by the public hospital were too strong for her, and she discontinued them. Currently, she purchases the medicines prescribed by the earlier private doctor whenever she has some money and stops them on days when she feels better. (Name changed, female, 55 years, diagnosed with diabetes one year prior to the interaction)

In some cases, patients also reported restarting their discontinued medicines after facing dire consequences (like a heart attack). Such patients often admitted to having 'learnt their lesson' on playing with medication. Adherence to treatment also appeared to benefit from the presence of supportive family members. In this regard, male patients frequently referred to their wives, who would remind them to take their medications and make wholesome meals for them to eat.

3.4 The constant balancing act between getting relief and lowering costs

This study was conducted in a context where people constantly struggled to make ends meet. We found that throughout their care-seeking journeys, people continually attempted to strike a compromise between the need for relief and the need for lowering costs. For instance, when poor health hindered livelihoods and daily routines, patients shifted from small private doctors to more expensive big private doctors. Conversely, when people felt better, and the symptoms were less severe, or the costs of big private doctors became burdensome, they shifted from private to public doctors and from costlier allopathic medicines to cheaper traditional medicines. People also tried to save costs by adjusting their treatment regimens- they took medicines intermittently, bought partial medicines, or continued medicines without regular check-ups. The following quotes emphatically illustrate the trade-offs that people make between saving money and getting relief.

“I am not able to take medicines regularly. The diabetes medicine I was advised, they are so expensive. If we have money, I get it (medicines). Otherwise, I take one Ayurvedic syrup. Only if my condition gets worse, I take the allopathy medicine.” (Female, 60 years, diagnosed with diabetes two years prior to the interaction)

“Now I am old, so they (the loom owners) don’t use me for running the machines. I am sitting idle for one and a half months with no work. If I go to the private doctor, he will give me two injections and three-time medicine and will take 100 rupees. If he writes medicine (to be bought) from outside, then 150 rupees. He gave me a strip of medicine from which I take half a tablet every day. (Male, 65 years, diagnosed with diabetes two years prior to the interaction)

The doctor lectures me and says that when he tells me first to get checked up and then take the medicine, I don’t listen to him. To save a few rupees, I buy the medicine from the shop and take it. (Female, 45 years, diagnosed with hypertension 16 years prior to the interaction)

Recognizing the inability of vulnerable population groups to pay out of pocket for chronic illnesses, health policies in India have endorsed the provision of free diagnosis and treatment for diabetes and hypertension through the public health sector (28). Our study found that, in line with this policy, care for diabetes and hypertension has been made available at select peripheral health facilities and the referral hospital in this area. But these services were perceived as being far from adequate by the community. The referral hospital in this area does have a specific cell for NCDs, but the doctor’s position has been vacant for the last six months. When we visited, an overworked substitute doctor was overseeing the diagnosis and the disbursal of medicines for a few NCDs. Also, we were told that medicines were not always available or sufficient. The public sector outreach workers associated with primary-level public health facilities were only partially trained and had not yet formally been assigned responsibilities pertaining to NCD care. Further, we found that the community was often unaware of the availability of NCD services in the public sector. People also shared past experiences of long waiting hours, rudeness of staff, and feelings of not being treated well in public facilities in the area studied. These experiences generally discouraged care-seeking from the public health sector or compelled patients to travel to better public hospitals in nearby cities in the metropolitan region when needed.

3.5 Lay perceptions: Notable absence of the concept of prevention of NCDs in communities

In our discussions with the community, we found that people were generally aware of both diabetes and hypertension. Women seemed to know more details about testing for diabetes and hypertension than men due to the checkups done during pregnancy. There was consensus that both were dangerous and disruptive to people's lives in many ways. Table 5 summarizes some of the perceptions of the community.

People's perceptions of diabetes and hypertension influenced their care-seeking journeys in many ways. For one, these perceptions did not engender the need for preventive lifestyle changes or early screening. It was believed that stressful events caused the body to be weak and precipitated such ailments. People believed that older age groups were more susceptible to stress. Since stressful and emotional life events were perceived as beyond the control of participants, notions of preventing diabetes and hypertension were largely missing from people’s narratives. Further, screening involved precious costs in terms of time and money; our discussions in the community suggested that people found it illogical to get screened for ailments in the absence of bothersome symptoms.

While people acknowledged the role of diet control as necessary in managing diabetes and hypertension after diagnosis, changing lifestyles and diets as preventive measures were not mentioned in the general community. Some patients/family members spoke of practicing diet restrictions, while others said it was challenging due to the lack of availability of healthy food where they worked. But we did not find any patients who emphasized the importance of exercise in managing these two NCDs. When we probed on this, some patients mentioned a lack of spaces near their houses to walk or exercise. Others did not consider doing exercise separately since they regarded their daily work as adequate exercise. As one female participant in a community discussion told us, “We have so much work in the household, we are on our feet, bending- whether it is filling water or washing, that is our exercise.”

Table 5: Community perceptions on diabetes and hypertension

Perceptions of the community	Summary notes	Sample quotes
Perceived etiology	Poor diet and stress were perceived as triggers of both diabetes and hypertension. Heredity and other lifestyle issues (lack of exercise, obesity) were not mentioned by participants as contributors. Religious beliefs also shaped perceptions of the causes and impact of the diseases.	*There is a lot of work at home, and if you don't pay attention to your food and drink, you can get BP (hypertension).* ***(Female, FGD 18-40 years age group)*** *When you sin, you get stressed and your health gets worse.* ***(Male, 67 years, diagnosed with hypertension 2 years prior to the interaction)***
Perceived symptoms	People shared that diabetes manifests as weakness in the body, aches and pains, wounds that do not heal, frequent urination and dizziness, and hypertension manifests as dizziness, anxiety, confusion and anger.	*I have heard that in sugar (diabetes), if there is any cut, it won't heal, the person gets weak, the eyes get weak, and the person gets thin. It is of two types; in one person gets hungry and, in another person does not get hungry.* ***(Female, FGD 30-60 years age group)***
Attitudes towards susceptibility	Most people believed that the young are not susceptible. Old age and tension were seen as precipitators. Both men and women were seen as susceptible.	*In young blood, you usually don't see BP (hypertension), sugar(diabetes). When a person gets weak, in old age, or has tension, then these things happen. (****Male, FGD 18-40 years age group)***
Perceptions of severity	Both conditions are perceived as interruptive of routines in many ways. Patients particularly noted the disruption in lifestyle pertaining to diet.	*BP (hypertension) is dangerous because in BP you feel dizzy and you can't do any work, you can't function, and the body becomes loose.* ***(Female, FGD 18-40 years age group)*** *Everything you can't eat (in diabetes), whatever you like to eat you can't eat. If you have to control too much, it is as good as dying of hungry.* ***(Female, FGD 18-40 years age group)***
Attitudes towards screening	The community did not find it rational or practical to seek care (screening or preventive measures) when there were no symptoms.	*No, we have not gone (for the screening test). We are poor, we don't have money to just go to do such tests without cause. Now we don't have anything (symptom) then why would we go for testing? (****Male, FGD 18-60 years age group)***

4. Discussion

We have structured our discussion in three sections. The first section discusses the study's contribution to conceptual thinking on care-seeking for NCDs in LMICs. The second section examines the study's key findings in relation to similar studies in other settings. The third section summarises its key lessons.

4.1 Cyclic care-seeking pathways for NCDs in LMICs: A framework

Figure 1 is our attempt to represent the diverse care-seeking pathways for NCD care encountered in our study in the form of a framework. Figure 1 depicts three cyclic components of the pathway: the initial care-seeking cycles (loop A), the diagnostic loops (loop B), and the disease-management loops (loop C). Loop A comprises the pursuit of symptomatic relief from 'small' private doctors and local pharmacies. People usually exit this loop only when their symptoms worsen, and they are unable to carry on with routine activities. On exiting loop A, people enter the diagnostic loops (loop B). Here, people embrace, confirm, or reject diagnoses. Diagnosis is not a single point in the patient journey but occurs repeatedly in a loop-like fashion. Intersecting with the diagnostic loops are the disease management loops (loop C). In Loop C, people initiate, adjust, stop, or restart disease management. In both loops B and C, care is sought from a mix of healthcare providers.

Figure 1: A framework of cyclic care-seeking pathways for diabetes and hypertension

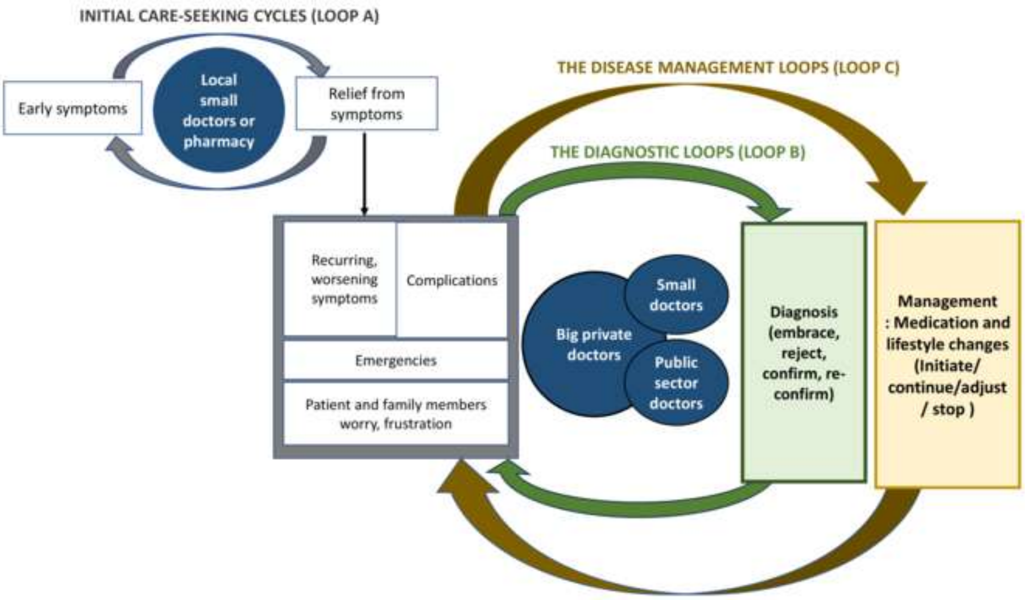

Figure 1 adds to current thinking on care-seeking journeys for NCDs. For one, the figure acknowledges that care-seeking journeys for NCDs are messy and cyclic in such settings; and cannot be linearly portrayed in simplistic ways. While Figure 1 does include clinical terms such as diagnosis, treatment, and adherence similar to earlier studies (11, 40, 41), these get considered as cyclic occurrences in our framework rather than as sequential events.

It can be argued that cycles are a positive phenomenon in NCD care-seeking and that the occurrence of multiple diagnostic and disease management cycles signals 'continuum of care' for these ailments (41, 42). But in our data, repeats in diagnosis or changes in the course of treatment, were typically not a part of meticulous ‘follow-up’. Instead, these repeats were often a response to previously disregarded diagnoses or poorly followed treatment advice. The cyclic pathways we have portrayed mimic being ‘stuck in a loop’ of care-seeking. In other words, our framework shows that care-seeking occurs as a ‘sequence of acute episodes’ (45), in a cyclic yet fragmented manner, which speaks to a poor continuum of care for NCDs.

Figure 1 also explicitly acknowledges the multiplicity of providers sought during the patient's care-seeking journey, a hard reality in many LMICs that has been given less importance in the current literature on care-seeking for NCDs. In summary, by acknowledging the messiness of the patient's journey, the cyclicity of various clinical touchpoints, and the complexity of providers involved, our framework attempts to add conceptual richness to current thinking on care-seeking pathways for NCDs.

4.2. Reflecting on our findings

We found that care-seeking for NCDs was convoluted, with many hops between diverse providers. People in our study area usually reported experimenting with three healthcare options- the local private sector comprising of 'small' doctors, the formal allopathic private sector, and the public sector. 'Small' doctors were usually Non-Degree Allopathic Practitioners (NDAPs) who lived close by. They were familiar, affordable, and convenient, but mostly, they could not diagnose and treat NCDs. The public health system was inadequate in terms of coverage, as well as considered as being non-sympathetic to people's felt needs. The formal private sector, comprising the 'big' doctors, trained in allopathic medicine, was both costly and unfamiliar to this population. Thus, none of the three healthcare options seemed to meet the needs and expectations of people living in the urban informal settlements we studied.

The reasons people reported in our study for hopping providers—such as costs, distances, quality of care, and patient satisfaction—echoed findings from other informal settlements in India, Kenya, and other African contexts (46, 47, 48). But, in a broader sense, the sheer number of doctor 'hops' in almost every patient journey points to a constant search for a 'better' suited provider. In other words, the 'hops' clearly signalled constant dissatisfaction with the care that people were receiving. From a policy perspective, the numerous provider switches were indicative of the urgent need for trusted and reliable 'first-contact' points for NCD care, as well as for the integration of care provided by different providers—two essential characteristics of good primary-level care (49).

The phenomenon of ‘hopping’ providers in our study also explains why the bypass of primary-level care, an important issue of policy concern (50, 51), is extremely challenging to comprehend in LMICs. Our data suggests that, with respect to care for NCDs, people do not ‘bypass’ one provider in favour of another. Instead, they experiment with multiple options for care, sometimes even simultaneously, and continually search for options that balance their need for relief and lower costs.

Our findings also point to delays in diagnosis and problems with treatment adherence. Diagnostic delays in our study had many causes, including the lack of providers who advised on necessary screening tests during the early stage of the disease and people's resistance to believing the diagnosis. We felt that there were many missed opportunities for early detection, an issue of concern in other LMIC settings as well (16, 40, 52). With regard to adherence to treatment for hypertension and diabetes, our findings were consistent with those reported in other LMICs; the cost of medicines, a lack of knowledge, unfavorable attitudes towards medicines, and a lack of belief about their efficacy were important barriers to adhering to treatment regimens (53, 54, 55). Similar to another study in urban India, we found that the lack of adherence to treatment regiments was intentional and did not stem from mere forgetfulness of patients. (56). In summary, though patients gave a variety of explanations for issues in diagnosis and treatment, these issues signal the absence of an affordable and integrated healthcare system.

4.3 Learnings from this study

From our findings, we suggest below three ways in which NCD care for people living in urban informal settlements in India can be strengthened.

First, the public sector needs to play a more active and integrated role in managing NCDs. Recent studies have shown that the public health sector in India is not being utilized adequately for the screening, treatment, and follow-up of NCDs (57, 58). One recent survey shows that, despite recent policy efforts, India's public primary and secondary care facilities are not adequately prepared to incorporate NCDs (59). Also, the public health system in India at present lacks the strong coordination mechanisms needed to effectively treat chronic diseases, since it has been historically designed to deal with acute conditions and infectious diseases (60, 61).

Second, the government-run NCD programmes in the country's urban areas can benefit from better engagement with the "small" doctors (NDAPs). The advantages of 'small' doctors in delivering first-contact primary-level care, such as their intimate ties to the community, responsiveness to the needs felt by the community, and affordability, have already been extensively discussed (62, 63). Concerns have also been raised regarding the level of care that 'small' doctors offer (64). Despite these concerns, small providers have been leveraged by the National Tuberculosis Control Program (65) and recently during the COVID-19 pandemic (66) to strengthen service delivery. In terms of NCDs, the role of these doctors has so far been limited. Since they are often the first points of healthcare contact for the community, their non-involvement speaks to a missed opportunity for the early diagnosis of NCDs. Their strong presence in the community also makes them ideal for follow-ups and routine caregiving for NCDs in urban informal settlements. Training this set of healthcare providers on NCD screening and diagnosis and leveraging their community networks to support the public sector in NCD care can go a long way in streamlining the care-seeking journey. While it is imperative to strengthen the public sector for NCD care, the role that the local private sector in such areas can play cannot be ignored (67).

Lastly, advice from neighbours and friends, as well as support from families, plays an important role in shaping people's care-seeking journeys. We found that while the community was aware of diabetes and hypertension as diseases, there was a paucity of knowledge about how the diseases were linked to lifestyle and heredity. Notions of ‘prevention’ and ‘screening’ for NCDs were entirely missing from community narratives. Raising awareness in the community is an important first step to optimizing the care-seeking pathway for NCDs. For doing so, others have suggested ‘educational’ interventions such as group communication, individual counselling, and mass awareness campaigns—including interventions led by community health workers and lay facilitators (68). Experiences from LMICs also tout patient ‘support’ groups as a valuable strategy for empowering patients, improving long-term adherence to medicines, and spreading awareness about NCDs (69, 70).

While the study offers fresh perspectives by analyzing patient care seeking journeys for non-communicable diseases in urban informal settlements, it has some limitations. One limitation arises from gathering information through memory recall. Some people could remember only the key highlights of their care-seeking journeys, such as the treatment during worsening symptoms or catastrophic health events. Often, patients did not relate several "every day" symptoms to their disease, providing little information about their journeys before diagnosis or about simultaneous journeys related to other diseases. We tried our best to specifically probe and clarify events. Since the patients were sampled through SNEHA's existing maternal and child health program in the community, participants included only those with families living in the informal settlements. We also did not have access to recently migrated male workers who were single and living in this area, and we acknowledge that their care-seeking journeys could have been different.

4.4. Conclusions

It has been recognized that empirical studies of care-seeking journeys can serve as important tools for policies to understand people's needs and expectations. Our paper aims to bring the experiences of people from urban informal settlements to the forefront of NCD care. Based on the features of the patient journey in our paper, we have discussed in Table 6 the key policy and conceptual learnings from this paper. We hereby call for more studies that do not assume a 'linear' care-seeking journey for NCDs but instead enable policies to work towards this ideal.

Table 6: Summarized learnings from the study

Conceptual learnings	Policy learnings
• New thinking on care-seeking pathways for NCDs must acknowledge the messiness of this process, and not shy away from accounting for non-linear, cyclic events in patient journeys. • In contexts like ours, frameworks to capture patient experiences must consider the plurality of providers available and sought. • A less complicated journey for patients should be a goal for policies on NCDs to work towards.	• The public sector in urban areas needs to be strengthened to adequately screen, diagnose, and treat diabetes and hypertension. We particularly advocate for outreach screening and follow-up in urban slums. • Non-degree allopathic practitioners are the ubiquitously available 'first-contact' points for healthcare in urban slums. Their presence and strong networks can be better leveraged to facilitate routine screening, diagnosis, and management of NCDs. • Raising awareness in the community is an important step in optimizing the care-seeking pathway for NCDs.

Finally, it is increasingly being recognized that urban areas are unique geographical spaces that need focussed attention (71). With regard to NCDs, the dominant perspective that the urban rich are more susceptible to this group of diseases in comparison to other sections of the population needs to change. Our study has shown that a lack of awareness and the delays in diagnosis of NCDs in urban informal settlements are likely to result in misleading estimates of disease-burden in this population. Thus, we call for more empirical research that focusses on NCDs in urban informal settlements.

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