

Investing in Improving Public Primary Healthcare Will Transform Indians' Care-seeking Journeys to Benefit Individual Health, Families' Financial Stability, and the Country's Broader Socio-economic Development

Policy Brief No. 3 | 2023 | Authors: Nossal and NCAER Study Team, Health Seeking Pathways in Four Indian States (4IS) [For any query, contact Prof Sumit Kane at sumit.kane@unimelb.edu.au]

Introduction

In India, approximately 75 per cent of primary healthcare is delivered by private, for-profit providers, ranging from formally-trained practitioners of modern medicine to a plethora of unqualified providers peddling all kinds of wares. Unqualified and sometimes predatory providers are often the most accessible care option for many, particularly the poor. India's poorly-regulated health system with few quality assurance mechanisms leaves all, particularly the poor, vulnerable to exploitation by unscrupulous providers.

Drawing on interviews conducted across twenty villages in India in 2019–20, our study (Kane et al. 2022) explores how patients with chronic illness have to make difficult care-related decisions, often with little, if any, reliable guidance. And how while making these decisions, they also have to navigate personal, family, economic, and cultural factors and a complex, fragmented healthcare system. We found that the absence of reliable, accessible primary healthcare left most patients running erratically between providers, taking wrong turns, and becoming disappointed, frustrated, exploited, and impoverished. Our study shows how a poorly-regulated health system with weak primary healthcare amplifies the medical, social, and financial consequences of an otherwise manageable chronic illness, and how these consequences are exacerbated among the most economically marginalised. Our findings underscore an urgent need to invest in accessible, good quality, and trustworthy sources of guidance and healthcare for chronic illness at the first point of call, to protect both individual and broader public health.

Key Policy Problems

- The current lack of trustworthy medical guidance leaves patients wholly responsible for making complex healthcare decisions, revealing a health system that fails to protect citizens in their time of need.
- Without a robust primary healthcare system, predatory providers emerge as the most accessible option for desperate patients and exploit the latter at their most vulnerable, with impoverishing consequences for families.
- Investment in high-quality, accessible primary healthcare services will protect vulnerable people from unqualified profiteering providers. This will promote individuals' health, families' economic stability, and a healthier, stronger India.

The growing burden of chronic illness meets a fragmented health system.

In India, the prevalence of Ischaemic Heart Disease is estimated at 14 per cent, high Blood Sugar at above 10 per cent, and Chronic Obstructive Pulmonary Disease at 7 per cent, highlighting the rising burden of chronic illness. Chronic illnesses and their care are both distressing and demanding. The burgeoning prevalence of chronic illnesses in India is likely to have cascading negative consequences for India's economic and social development if patients are unable to access reliable healthcare. As Indians tend to develop cardiovascular disease earlier, these chronic conditions often affect household breadwinners, with devastating economic impact on families. The potential of chronic illnesses amid a poorly-regulated health system becoming a major economic development and social problem for India is clear.

We need to better understand patients' healthcare-seeking journeys.

Research on healthcare-seeking in India has explored the under-utilisation of public health services; this literature shows that Indians' choices are underpinned by factors including traditional belief systems, lack of confidence in public services, financial constraints, stigma, and taboos (Pati et al. 2013; Kapoor et al. 2012). Building on this literature, our study (Kane et al. 2022) aimed to understand the choice of providers, the costs incurred, and broader healthcare-seeking journeys among patients experiencing chronic severe breathlessness. We conducted in-depth interviews with 41 respondents across 20 villages in the States of Uttar Pradesh and Maharashtra. We found two distinct stages in people's healthcare-seeking journeys—each with its own unique vulnerabilities, and each requiring careful policy consideration and intervention.

Stage I: Running from pillar to post in search of a 'cure'

“जो भी डॉक्टर आस पास थे हम गए...दस पंद्रह कम से कम”

“[I visited] whichever doctor was available nearby ... we may have gone to at least 10–15 doctors.”] - elderly woman, Uttar Pradesh

The beginning of participants' healthcare-seeking journey, often triggered by an acute exacerbation of the illness, was characterised by urgency and desperation, as patients hoped and searched for a 'cure' and made intensive efforts to seek it. Patients' narratives revealed that healthcare-seeking was a family matter underpinned by strong social, cultural, and moral dynamics: the family rallied to mobilise all possible resources to find answers. The narrative of 'leaving no stone left unturned' in efforts to find a 'cure' was repeated by nearly every respondent, highlighting the cultural importance of being seen as doing everything possible for a loved one facing a health issue.

Revealing a limited understanding of their chronic (incurable) health condition, patients described an urgent desire to eliminate illness by 'uprooting it'. This preoccupation with “जड़ से

निकल जाए” (that is, uprooting) led them to run erratically between healthcare providers—from *jholachhaps* (quacks) to traditional healers to qualified doctors, often all at once. In this phase, unqualified healthcare providers who charged modest fees to dispense medicines and give injections emerged as usually the most accessible healthcare option and were by far the most common first providers for the patients.

“गरीब सिर्फ इन्ही (झोलाछाप) के पास ही जा सकता है... बाकी भगवान की मर्जी”

[“The poor can only go to local (unqualified) doctors and leave the rest to God.”] -an elderly man in Uttar Pradesh

Beyond moral and familial obligations, healthcare-seeking actions were circumscribed by real-world, intra-household financial barriers: treatment decisions were ultimately based on how much money the family could spare. Palpable tension emerged between the narrative of leaving no stone unturned, intra-household resource allocation, and contingent healthcare-seeking choices.

Desperation, hope for cure, and cultural obligations intersect to create exploitable vulnerabilities.

In this phase, the patients' mix of hope and desperation for answers drove them round in circles, leaving them wholly vulnerable to financial exploitation by unscrupulous providers. The respondents described being misled, receiving inappropriate care, and being manipulated by providers who would exaggerate their illness, recommend costly unnecessary medicines, and collect commissions from unnecessary referrals.

“We had to sell all of the three plots (of land) that we had ... all that money was spent on his treatment.” -son, Uttar Pradesh

“If our father would have been fine, then we would have continued our studies ... we had to leave our studies.” -daughter, Uttar Pradesh

Alarmingly, but perhaps unsurprisingly, the respondents reported resorting to selling assets, incurring debt, reducing essential expenditures, and foregoing opportunities (that is, children's education) to finance their treatment. Families

where the main breadwinner was the patient fared the worst.

Stage II: frustration, reconciliation, acceptance

“यह दम तो दम के साथ ही जाएगा”

The second phase of the respondents' journeys was marked by reconciliation, acceptance, and a shift from finding a 'cure' to finding relief. Once they identified what medicines brought relief, the patients pursued these remedies, irrespective of whether they were technically correct and whether they were being monitored for side effects, raising concerns regarding the inappropriate use of medicines such as steroids.

“The disease has overpowered me ... I have been defeated at the hands of this disease.” - middle-aged man, Maharashtra

Despite now managing their chronic illness themselves, the respondents continued to report a sense of despair, disappointment with themselves, and personal failure stemming from their illnesses. These narratives reflect their low expectations of the health system and highlight the absence of meaningful mechanisms to protect people from health-related risks. Our study found that in navigating the social and moral obligations to show that no efforts had been spared in seeking to 'cure' the chronic, lifelong (incurable) illness, the respondents took many wrong turns and stumbled into many blind alleys. A common feature underpinning all these experiences was the lack of reliable information and guidance about the illness, its nature, its chronicity, and appropriate treatment for it—not just at the beginning of healthcare-seeking, but throughout the illness.

As a matter of serious concern, this second stage was characterised by many patients settling for what gave them symptomatic relief. This, in turn, often meant a sustained, long-term trajectory of financial exploitation, or worse, resorting to incorrect or dangerous disease management approaches.

Conclusions

We found that in the absence of trustworthy guidance, patients seeking healthcare became lost in

the complex maze of India's poorly regulated health system. While people bravely navigated uncharted terrain of overlapping personal, familial, moral, economic, and cultural obligations and difficult health systems spaces, they were often led down wrong paths by unscrupulous providers. The notion of a journey without a clear route and many uncertain turns and blind alleys defined the respondents' experience, given that the patients did not know what they were suffering from, the right places to seek advice and treatment, whether a healthcare provider was appropriate and trustworthy, and what outcomes to realistically expect. Our findings also show that the respondents' families needed to be seen as doing everything possible to cure their loved one—an imperative underpinned by the weak health-related social protections in India. This imperative had potentially catastrophic implications for poor families in a context rife with unqualified, exploitative healthcare providers. Our study highlights the urgent need for investing in ensuring reliable, high-quality, accessible primary services to protect all Indians, particularly the poorest.

Policy Implications and Recommendations

Our study found that the patients' initial care-seeking stage is when people are most desperate, and therefore most vulnerable, to being misled and/or exploited by unscrupulous, profiteering healthcare providers. In their frantic search to 'cure' their incurable condition, people resort to 'distress spending' in the form of selling assets, borrowing at extortionist rates, and foregoing educational opportunities for their children, which for the poor and near-poor can be disastrous. Poor families were left wholly responsible for making complex healthcare decisions, which had devastating financial consequences. From a policy perspective, respondents' central narrative of leaving no stones unturned exposes the very problematic normalisation of the absence of reliable primary care services in rural India.

Our study provides compelling evidence that India must strengthen its primary healthcare.

Our findings pinpoint the absence of accessible, good quality primary healthcare as a critical health system gap. Extending the insights from the

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literature on the poor technical quality and poor responsiveness of care in India, the most common gap for our respondents was the unavailability of reliable and trustworthy primary healthcare close to their homes. The respondents' accounts show that the choice of first provider is critical. It can support a faster, less expensive realisation that chronic illness cannot be cured, and a swifter transition to the (less economically damaging) state of managing the chronic illness. Our findings demonstrate that the absence of reliable primary healthcare promotes the proliferation of predatory, superficially affordable providers, whose low price misrepresents their potentially catastrophic economic and health consequences. It is this dearth of responsive, reliable, and geographically accessible healthcare providers for providing timely guidance that drives poor patients down the path of desperation, disappointment, and financial damage. Such services are urgently needed to protect not only individuals' health, but also their families from impoverishing, drawn-out journeys towards finding appropriate care and the country from the devastating socio-economic impacts of a massive, ill-managed burden of chronic illness.

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To protect patients from exploitation at every stage of their care-seeking journey, India must invest in robust primary healthcare services.

Establishing trustworthy sources of guidance and care at the first point of call is critical, especially for the poor. Our findings call for investment into public healthcare services towards ensuring that such services reach vulnerable people before predatory, unqualified providers do. While the challenges in investing in public healthcare are documented, recent research has demonstrated that even modest investments can yield significant gains (Mulcahy et al. 2021).

Further, investments in improving public healthcare services will indirectly aid in regulating the private sector through regulation by competition (Mc Pake and Hanson 2016).

Providing accessible, responsive, good quality public services to meet patients' needs at the first point of call will undermine the appeal of predatory providers and crowd them out of the healthcare market.