Migration for healthcare: exploring access to healthcare as a factor for internal migration in India

Introduction

People living with chronic medical conditions have travelled across geographies through centuries in pursuit of treatment, conducive climates and technology (Bennett, King, & Milner, 2004; Bookman & Bookman, 2007). Human movements to access better healthcare facilities, spanning across the spectrum from spiritual to biomedical, is rather commonplace across the globe. Over the last two decades, academic and policy attention, in this context, has been primarily focused on medical tourism, a deeply contested term, which primarily implies a North-South Movement for affordable and, most often, elective medical treatments(Connell, 2006; Kangas, 2010; Turner, 2007). Within this more extensive, one-size-fits all umbrella term, intra-regional and domestic movements for healthcare emanating from unequal regional development and other factors like war, violence,etc., are often subsumed without much attention. Over the decades, the terminologies have moved towards an increasingly critical understanding of the phenomenon, conscious of its social, political and economic underpinnings(Roberts & Scheper-Hughes, 2011).

Intra-regional travel for medical treatments precedes the development of medical tourism in the region. Recent studies have shown that intra-regional travel within South Asia is an important aspect of human mobility in the region and needs closer scrutiny to explore various facets of medical travel(Hudson & Li, 2017). Very interestingly, Hudson and Li (2012) quote Cohen (2010) highlighting that the emergence and expansion of the medical tourism market are owed more to the intraregional movement of medical travellers in the developing world, and medical tourism from the west to these destinations began only after the medical hubs were well-established. The trajectories of intraregional migration for healthcare are varied but follow preexisting and fairly established patterns of labour migration as in the case of Bangladeshi

health-seeking migrants in Singapore (McNamara, 2020) andother forms of South-South medical travel (Ormond & Sulianti, 2017).

India is one of the leading global destinations for medical tourism and South Asia as a region is the focal point of medical tourism in the world.While the income and opportunities ushered in by the medical tourism boom has been a significant contribution to the region's economic development, it has simultaneously highlighted the glaring inadequacy and inaccessibility of quality healthcare for India's low-income patients (Sengupta, 2010). In this context, India makes an interesting geographical and social space, wherein access to quality healthcare is tooirregular, varying not only by region(Purohit, 2004) but also determined by class, caste, gender among other factors. Moreover, illness and disease are important contributing factors to poverty and households falling into poverty in India and other parts of the developing world (Krishna, 2004).

In an extremely mobile society, like India, internal migration is diverse, a phenomenon across caste, class, gender and other social locations. The focus has been primarily on labour migration, which does constitute a large proportion of migrant movements. In the wake of the COVID19 pandemic and the subsequent migrant crisis in India, it can be claimed that migration is a reasonably well-researched but poorly understood as a social and cultural phenomenon in the country. Migrant movements to access healthcare, despite being a popular mechanism to cope with the unequal development of health infrastructure and services in some parts of the country, remains an underexplored area of study. While I understand migration for healthcare as a distinct process with nuanced intricacies, to study it within the realm of migration in India's context enables one to widen the knowledge on migration and push beyond the binaries of push and pull.

In this paper, I focus on internal migration for healthcare in India, looking specifically at cancer patients migrating to access healthcare to the metropolitan city of Mumbai, Maharashtra. Through an urban ethnographic approach, I draw from the everyday life of migrant patients and their families and caregivers, to explore the phenomenon of migration for healthcare as it pans out in urban center in India. How does this contribute to the broader debate on migration patterns? I conceptualize migration for healthcare as the phenomenon of travelling to another destination, usually inter-state, to access medical treatment for chronic conditions over a period

of time. I go with the term healthcare, instead of medical, as the participants of the study are migrating to seek secondary and tertiary medical treatment rather than elective or advanced treatments, and this results in crucial differences in experience.

The ethnographic study locates the migrant for healthcare at the crossroads of migration, health-seeking and the urban space. In the nextsection, the phenomenon of migration for healthcare is analyzed within the public healthcare context of India, tracing the country's experience with healthcare as a public good and the neoliberal turn in the 1990s. The lack of affordable and quality public healthcare is the main push factor for individuals migrating to access healthcare. In the third section, I draw from ethnographic interviews with patients and their families in Mumbai, seeking cancer care at a prestigious oncology hospital. Through a glimpse of their everyday life in the city, the paper explores vulnerabilities and challenges which characterize the migrant journeys of those seeking access to healthcare. In conclusion, I argue that it is essential to conceptualise migration for healthcare as distinct from other forms of migration, internal labour migration, as well as medical travel.

While migrants of healthcare are most often referred to hospitals in these cities by their local referral hospitals, the role of the hospitals in the city is limited to providing medical treatment. Most Public hospitals in the cities do not have the required infrastructure to assist and accommodate a large number of local and outstation patients seeking healthcare and patients, and their family members are often left to fend for themselves in unfamiliar cities and a diseased situation. Such a scenario necessitates the study of this kind of an illness experience which is lived daily by the large numbers of migrant patients and their family members. Such an illness experience is not limited to seeking treatment but is characterized by an unanticipated and in most cases,an unwanted encounter with the city.

Exploring migration for healthcare and India's healthcare trajectory

Historically, cities have been hubs of medical care also providing tertiary and quaternary care to the rural populations of the nations. In a post-neoliberal world, the nature of cities has undergone a tremendous change with global capital pouring in and shaping cities in instrumental ways. In contemporary times, cities as concentrations of medical care have been taken to a global level with the advent of private hospitals and clinics tapping into world-class medical expertise, technology, and facilities, and attract local and global patient-consumers(Connell, 2006; Kaspar & Reddy, 2017)

While independent India ushered on a journey of development with particular focus on health and education with conscious investments in these sectors, the shift in development approach of the 1980s changed the contours of development in the country to a growth-centred paradigm, expecting the benefits of economic development to 'trickle down'. The subsequent growth of the private sector in medical care, shifts in investments exclusively into population control created pressures on the existing healthcare planning and structure to change, and the Structural Adjustment Plans of the International Monetary Fund and the World Bank made unprecedented healthcare reforms a must in India (Qadeer, 2000). Health sector reforms promised an approach of innovation in the planning and execution of health systems and introduced terms like 'new public management' and 'public-private partnership' with the potential to invigorate health systems in the developing countries (Berman and Bossert, 2000). However, the way the structural adjustment plan panned out vis-à-vis the Indian context and other developing economies, the health system suffered irreversible cuts in public sector investment in healthcare, donor-driven priorities of health planning and management were initiated and privatization of medical care accelerated (Qadeer, 2000). The majority of the private sector in healthcare continue consisting of individual, qualified, unqualified or underqualified practitioners, providing primary level, out-patient care and are located both in urban and rural parts of the country. In secondary healthcare, many nursing homes of varying bed strengths, quality and capacities are mainly concentrated in urban areas except for states where private sector growth is high. Tertiary care provision by the private sector is limited to large cities and consist of multi-

specialty hospitals offering in-patient and out-patient care and have grown to become one of the biggest beneficiaries of government subsidies in the form of loans and land (Baru, 2006).

The historical trajectory of healthcare services in India has led to significant gaps in health services predominantly in the secondary and tertiary sector in rural India and with a concentration of private and public, and secondary and tertiary services in the cities of the country. What is often called 'the urban bias in healthcare' (Connell, 2011), then becomes a factor necessitating internal movements for healthcare from rural areas and small towns to cities. The dominance of the private sector as the choice of healthcare provisioning in the country is presently much more than the public-sector healthcare services (both in-patient and out-patient) in both urban and rural areas. Seventy-five percent out-patient care is provided by the private sector while 55 percent of in-patient care is received from the private healthcare providers. And yet, the use of public hospitals continues to have a 'pro-poor' trend with people in the lower-income quintiles using public hospitals more than those in the upper quintiles. There is also a sharp increase in the average expenditure on healthcare as assessed in the 71st round of NSSO data. Amidst the debates on universal health coverage and a health insurance led approach to universalizing healthcare, it is interesting to note that coverage of government-funded insurance schemes is only 13.1 percent in rural India and 12 percent in the urban areas. The benefits of the government-funded insurance schemes have not reached the neediest patients. They are still far from providing financial protection (Sundararaman & Muraleedharan, 2015) and raise concerns regarding the insurance-led healthcare schemes being introduced as public-provisioning of healthcare services in the country.

Nearly 70 percent of India's healthcare expenditure comes from the household's Out of pocket Expenditure, while the government contribution is limited to one-fifth of the total 4.2 percent of the GDP spent on healthcare in India. Such a pattern of OOP expenditure has found to have a visible implication on impoverishment and catastrophe owing to healthcare expenditure (Selvaraj and Karan, 2012). Out-of-pocket spending is any direct expenditures by households, including all kinds of payments to health practitioners, suppliers of pharmaceuticals, therapeutic appliances, and other goods and services for improvement in the health of individuals and is typically a part of the private health expenditure. Healthcare in low and middle-income countries

is often paid for out-of-pocket by the people. It is well known that high out-of-pocket spending for health brings financial burden on families and it also influences the health-seeking behavior with delayed treatments (Ravi et al., 2016). Catastrophic spending on health occurs when a household reduces its basic expenses over a specified period, sells assets, or accumulates debts to cope with the medical bills of one or more of its members (Ghosh, 2011). Studies in India show that the chances of impoverishment owing to catastrophic health expenditure is higher among rural households as compared to their urban counterpart and also among those who seek private medical care rather the public health facilities (Mondal et al., 2010). The lack of robust and quality public health infrastructure in rural areas makes rural populations increasingly at the risk of seeking treatment from private facilities and hence incurring substantial health expenditures.

The impact of macro policies and expenditure trends on healthcare trickle down to the lives of the most marginalized in our country in the form of financial burden sometimes escalating to high levels of debt, catastrophic payments and a cycle of impoverishment which becomes difficult to overcome. While infrastructural deficits vis-a-vis public healthcare facilities is a characteristic of the lives of many in India, the impact of expenditure on healthcare may have negative repercussions on essential aspects like education and nutrition of other members of the family as well.

The phenomenon of migration for healthcare exists across a rural-urban continuum with individuals and families moving to the cities to access medical treatment for prolonged periods. Sharma and Naraparaju (2017) explain that according to NSSO data for tourism in 2014-15 alone, there were 36.6 million health and medical related trips in India. Of these, 28.7 million in rural areas and 7.9 million in urban areas and 92% of the trips are within boundaries of the state. More than 60% of these trips are in the states of Uttar Pradesh, Maharashtra, West Bengal, Tamil Nadu, Bihar, Kerala, and Rajasthan. The average duration of a health-related trip is two days, and it is assumed that these trips are not for severe health conditions. The average expenditure per health-related trip is 13, 654 rupees in rural areas and 21, 437 rupees in urban areas. Being the only official source to gauge the internal movement for healthcare, the numbers suggest that while only 8% of health and medical related trips take patients and their family members outside

the state boundaries, the number remains considerable. In cases of complicated and chronic medical conditions, these trips can be as long as over a year as in the case of cancer.

To places of belonging: from where migrants for healthcare come

> In our village there is no doctor or hospital to go to but there is a compounder who can be called for in case somebody is sick. Most often his golis (tablets) work and there is no need for doctor and all. It is not like he has studied dactari or anything…but he can read and write and for one year he worked at a medical shop in Bettiah. This is how people learn…so he can give injection; he has tablets for all diseases. He is called to our house also when the men are unwell or anything. He is the doctor in our village…he treats everyone. If there is something that he doesn't understand or his golis don't work, then he only suggests taking the patient to Bagha…where they say big doctors sit in hospitals. But in the village, everyone trusts the compounder with all treatment…old, young, everyone.
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> Dulari Devi, 36.

Dulari's account of her experience with health care in a very remote village in Bihar is reflective of the still very elusive nature of basic health care in pockets of the country. She is accompanying her husband for cancer treatment in Mumbai. While the health care system in the rural parts of India has not extended and expanded adequately, especially in states like Bihar, newer health concerns have definitely seeped into these spaces with the people including —medical practitioners having nominal knowhow about a condition like cancer in which early detection is the key to effective treatment. The absence of good quality, institutionalized and accessible network of medical care and treatment results not only in delay in the right treatment worsening the medical condition but also depleting already meager financial resources of the patient and the family

The participants of this study came primarily from villages and small towns with very few of them hailing from smaller cities of the country. A majority of the research participants belong to States which have shown poor demographic indicators and have a significant percentage of their populations below the poverty line. States like Bihar, Jharkhand, Madhya Pradesh and Uttar Pradesh lag behind the national average in healthcare and have been historically deemed as the "demographically sick" states of the country and continue to face deficits in healthcare

infrastructure and services resulting in poor health outcomes. Apart from healthcare services, these states, along with states like Orissa and West Bengal fare poorly regarding poverty. According to the OECD Economic Survey, data from 2011-12 indicates that the states of Assam, Bihar, Jharkhand, Uttar Pradesh, Orissa and Madhya Pradesh fall below the national average regarding rural poverty and West Bengal and Maharashtra only do slightly better (OECD Report, 2017). The regional and spatial disparities of income are reflected in the inability of poor patients in these states to seek private healthcare and instead, embark on city-ward journeys to access public-funded and affordable healthcare services. It is also important to highlight that considering the rampant rural poverty in the states above, the burden of healthcare expenditure for patients from these states is magnified in the instance of a necessary migration to the city to access healthcare, creating a continuum of poverty and deprivation into their lives in the city.

The region and states from which the research participants belong are also indicative of the social and cultural variations which exist not only amongst these states but also concerning the urban agglomerations like Mumbai and New Delhi, which boast of a cosmopolitan culture. Aspects of everyday life like food habits, language, routine and ways of interpersonal exchange vary in significant ways, and these diversities stand out uniquely in the almost homogenized urban landscape. Amidst the discussion on economic differences and social and cultural diversity, one ought not to forget the sheer physical distance which separates these spaces spanning from a distance of not less than 1000km in the case of most participants. The vastness of the distance along with arduous train journeys increases the difficulty of mobility, restricting patients and their family members to commute regularly between these distant locations. While distance and crowded trains are factors discouraging patients' mobility back to their homes, the uncertainties associated with illness and their lack of understanding of the illness condition are essential in understanding the reasons why patients and their family members prefer to remain within proximity to the hospital during their treatment.

> "Before coming to Mumbai, we spent 1 lakh on treatment for the illness. We did many tests for my wife, 3-4 hospitalization in Raipur, and so many expensive medicines and

> treatment for 4-5 months. Doctors told us it is a simple infection, but things never got good. We felt cheated, all our savings are gone before we were referred to Mumbai."
>
> Mukesh, Chhattisgarh

Mukesh, is accompanying his wife for cancer treatment and his narrative explains the frustrations of accessing affordable and quality healthcare in even capital cities of native states. In most cases, patients and their family members spend huge amounts of money before reaching a reliable and quality healthcare service. Many participants also raised concerns about their lack in trust in local private and public hospitals, leaving them with no other option but to journey to the city for trusted options in healthcare.

Patterns of Migration for healthcare

> After getting treatment from the local doctor and ayurvedic doctor in Saharanpur for about six months…without any improvement in the condition of my husband's ulcer of the mouth, the doctor finally asked us to go to AIIMS in New Delhi…the first emotion was obviously very difficult…we got a sense that it is something serious. From Saharanpur, where we lived, Delhi is 5 hours away by train…so going to Delhi was not very difficult at least to think about. I quickly spoke to my neighbours and they agreed to look after my children during the day and feed them. I would make all arrangements for their school and take a train at 4:30 am to reach Delhi around 9 For the first few days we commuted daily from Sarahanpur…it was very difficult and tiring but we could come back to home and our children. Treatment at AIIMS was very slow…we would get time for OPD once in 7- 10 days but would have to be there for test, reports and all that. Then we contacted our guruji in Saharanpur and he told us that we can go live in the gurudwara (Bangla Saheb) in dilli…then things got a little convenient. We knew about Delhi from people…our local MLA was also helping us with his contact in AIIMS…although it was our first time in Delhi or in any other big city, the people were like us, it was easy to understand directions, food was like what we ate. After waiting for 6-7 months to get regular treatment in Delhi, our doctor referred us to Bombay.
>
> Anita Verma, 43

Relocation to the city to access healthcare, in most cases, looks like the relocation of the entire household. The patient is accompanied by a female family member who becomes the primary informal caregiver. She is either the spouse, mother or sister in most cases and is responsible for food, clothing and other aspects of daily routine which women traditionally look after. The role

of the female caregiver also has affective importance in most cases. Patients are often also accompanied by a young and male relative, usually from the same village to assist the family in negotiating the complex urban systems and enable them to access all available services. This kin isusually literate and is responsible for helping the patient get charity and donations from the various trusts across the city and assistance in the hospital. In cases, where the female caregiver is literate, she takes up the roles and responsibilities of the kin and provides all forms of support to the patient. There are instances when patients especially those from nuclear families are compelled to bring along young children to the city, not only disrupting their education but also risking their health and safety in the unfamiliar city spaces.

However, very often some family members return to the village and are replaced by others. During the agricultural period, many of the caregivers who work on the field are replaced in the city by older family members for a brief duration. It is also common for relatives and friends from near and far to visit patients in the city and become part of the phenomenon of the migration for healthcare.

Most participants of the study belong to villages, town, and cities in states with poor healthcare infrastructure and a higher incidence of poverty than the national average. Migrants for healthcare are compelled to undertake a journey to the city owing to the lack of quality healthcare services which are also affordable within proximity to their places of residence. However, the journey of the patient to the cities like Mumbai and Delhi are not the first preference in the case of most patients, which is obvious for practical reasons like referrals required, but also characterize the experience of seeking healthcare for cancer patients. Migrants for healthcare make considerable Out of Pocket expenditures over a period of some months before the diagnosis is confirmed.

The participants of the study report expenditure on medical services including doctors' fee, diagnostic tests, medicine, hospitalization, and surgeries amounting up to rupees 1 lakh before they even reach their destinations in the cities. With private hospitals and practitioners reaching remote locations and often projecting an image of technological advancement and quality, many participants avail such medical services and end up spending huge amounts of money with

hardly any benefits in the treatment process. However, the spending is not limited to the services offering treatments within the Western medicinal paradigm, and many participants of the study have engaged in Ayurveda and Homeopathy treatments along with some cases where money was spent on spiritual healing by taking the patients to spiritualbabas and temples.

Expenditure is one aspect of the experience of medical treatment before reaching the city and accessing its health services. It is coupled with the common incidence of unjustified delays in seeking treatment and seeking inappropriate and wrong treatment. Especially in the case of cancer treatment, where delays in appropriate treatment can become a matter of life and death, the psychological impact of delayed treatment is immense amongst participants. However, even upon reaching the city and accessing treatment in the hospital, many participants continue to engage in alternative treatments like Ayurveda and natural remedies, sometimes secretly, ensuring that their journey into the city is not equivalent to a rejection of local and cultural healing practices.

In most cases, after the nearby town, patients travel to the closest city with available medical service and most of them preferred hospitals which are either run by the government or by charitable trusts. This movement to a nearby city can be understood as migration to an intermediate location before having to travel to larger cities. Migrants for healthcare choose cities and towns which are within proximity and offer assistance through existing networks. For example, Vicky decided to seek treatment in Patna owing to some villagers who worked in the city and could help with appointments, food and a place to stay for the family in the city. On the contrary, Janaki Devi and her husband chose Varanasi for treatment owing to physical proximity to Varanasi added to their familiarity with the pilgrimage city. Patients follow different trajectories and use their networks and social capital to access medical treatment in such a scenario. Both Vicky and Janaki Devi belong to Bihar and yet choose to seek treatment in two different cities. While Vicky depends on migrant networks to facilitate treatment, Janaki Devi relies on networks of ‘spirituality’ to arrange for the process of treatment.

Livelihoods left behind

A chronic condition like cancer in the family translates into disruption of work and regular life. For low-income households, it also means unprecedented financial difficulties. The occupational profiles of the research participants of the study indicate that most families have some or the other source of regular income and while the income might be small and insufficient to pay for healthcare, the families would not fall into the category of 'poorest of the poor'.

> "I am from Darbhanga district in Bihar, but work in construction in Hyderabad for the past 8 years. We have 2 acres land in the village, my father and women of the family look after agriculture. Now I am not fit to work in construction at all, so the whole family and my treatment is dependent on land only."
>
> Deepak, 37

While participants like Deepak have been migrant laborers earning in Hyderabad for the last eight years, many participants own and cultivate small tracts of agricultural land in their villages. Others have salaried jobs in the private sector, in the wake of illness and extended leave from work, there are no expectations of any financial support. Many participants also ended up selling/ mortgaging land to pay for their medical treatment, and apart from the mounting debt, do not also have any means of livelihood to return to. Regarding livelihood, the differences are vast, and while some participants have the comfort of owning land, others have a somewhat hand-to-mouth existence. What is common to all participants is the financial and social capital to undertake the journey to the city, with as less as 500 rupees in their pockets. The occupational profile of participants raises concerns about the inability of specific populations to become migrants for healthcare.

Owing to their extremely vulnerable financial situation, many migrant patients or their family members are compelled to do odd jobs in the city, to meet daily expenses. Many of them take up jobs in the hospital's vicinity like NGO volunteers, security guards and also tailoring and stitching jobs offered by some NGOs. Many of these migrants for healthcare merge seamlessly into the labour migrants of the city- not only sharing livelihoods, but also housing and existing migrant networks.

Conclusion

This paper only presents a glimpse into the lives of migrants for healthcare in the city of Mumbai, and their journeys characterized by frustrations and loss but also hope. While access to oncological care brings them to the city, everyday life in Mumbai goes beyond the medical aspect of the migration process, and as many participants highlight, making a living in the city becomes as important as accessing medical care, for some.

A socio-economic profile of the participants of the study provides important insight into the lives and experiences of migrants for healthcarebefore their journey to the city and sets the context for a study of their everyday lives in Mumbai. The experiences of the participants indicate that the states which lag behind regarding national averages of development indicators send many patients to seek treatment in the cities. Patients often travel through thousands of kilometers to access healthcare in the city,and this journey is no short commute, as one may imagine.

Among the participants of the research study, it was common for participants to go to other cities and towns before being referred to Mumbai for treatment and make significant amounts of Out of Pocket expenditures on not only private healthcare but also on alternative medicine and healing practices, which turn out to be ineffective in most cases. Regarding livelihood, participants have some source of steady income at their place of residence or are engaged in the informal sector as labor and private salaried jobs. The occupational profile reflects the financial status of the families and indicates that participants in the study had or could arrange the prerequisite financialand social capital to undertake the journey to the city. The narratives presented in this paper enable us to understand the phenomenon of migration for healthcare in depth, highlighting aspects which establish that movements for healthcare need to be seen as distinct from both popular understandings of internal labour migration as well as international and intraregional medical travels.

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