

Chapter 10

Joining the Conflicting Spheres: Travel in Balancing Work, Life, and Treatment for Female Tuberculosis Patients in Bengaluru City, India



Sobin George, Prajwal Nagesh, and Ajay Bailey

Abstract Evidence suggests that inadequate access to transportation services adversely affects labor market participation and healthcare accessibility for vulnerable populations in cities of the Global South.

1 Introduction

Evidence suggests that inadequate access to transportation services adversely affects labor market participation and healthcare accessibility for vulnerable populations in cities of the Global South (Weber et al., 2010; Fletcher et al., 2017). Lucas (2012) found that transportation planning in cities that neglect socio-spatial inequalities can exclude marginalized and vulnerable sections of the population. For example, the impacts of inadequate access to transportation can be significant for working women from lower socio-economic backgrounds since travel is an integral part of their everyday life. Drawing on the framework of the “right to city” developed by Harvey (2003), this chapter attempts to understand how disadvantaged laboring women access work and health care in the cities of the Global South. In these contexts, characterized by neoliberal urbanization and resulting inequalities, there is often a “dispossession of the urban masses of any right to the city” (Harvey n.d:12). Specifically, this chapter examines the access of female tuberculosis (TB) patients involved

S. George (✉)
Institute for Social and Economic Change, Bengaluru, India
e-mail: sobin@isec.ac.in

P. Nagesh
Institute for Social and Economic Change, Bengaluru, India
e-mail: p.nagesh1@uu.nl

A. Bailey
Department of Human Geography and Spatial Planning, Utrecht University, Utrecht, The Netherlands
e-mail: a.bailey@uu.nl

in informal work environments in Bengaluru, India, to transportation services. It explores how their daily travel experiences intersect with their work and health-care access, shedding light on the implications for urban exclusion and the balance between work, life, and treatment.

2 Methods

While this study primarily focuses on access to urban transportation, it also contextualizes other aspects of neoliberal urbanization, as described by Harvey (2003). These include spatial exclusion and marginalization of the poor to the peripheries of society due to capitalistic expansion, poverty, and precarious work and life conditions, as well as intersections with gender. Hence, the study adopts an analytical lens that focuses on the gender intersections of urban exclusion, poverty, and informality. Data for the study were collected through in-depth interviews with 80 female TB patients who were actively engaged in work and undergoing Directly Observed Treatment, Short-Course (DOTS) treatment. These interviews took place between January and August 2019 and were conducted at 18 public health facilities (DOTS centers) exclusively dedicated to TB treatment across four regions of Bengaluru City. Participants were selected purposively from a baseline survey conducted at the DOTS centers. Written consent was obtained from each participant prior to the interview.

The sample consisted of 35 pulmonary and 45 extra pulmonary TB patients, as indicated in Table 1 (also refer to annex). Out of the 80 female participants included in the study, 55 were between the ages of 15 and 34, while 19 were in the age group of 35–44. Among the participants, 10 were unlettered. With the exception of 6 individuals, all participants were engaged in casual employment in various settings, including small factories, retail shops, hospitals, small restaurants, schools, beauty salons; some engaged in public and domestic work. All Interviews were audio-recorded and transcribed; each interview was translated to English from the local language of *Kannada*. The data were anonymized, and the names of the participants used in this chapter have been changed. The analysis of the data was conducted using the qualitative software *Atlas-ti 7*.

3 The Life World of Female TB Patients: Conflicting Spheres of Family, Work, and Treatment

Balancing the spheres of work, life, and health care emerged as a prominent theme from the interviews. Participants expressed numerous unmet needs and encountered challenges when it came to striking a balance between their work, life, and TB treatment. Managing household responsibilities, maintaining intimate relationships, and sustaining social connections posed significant difficulties for them after being

diagnosed with TB. Married and employed women often reported a pervasive lack of empathy and care from their family members. Despite being infected with TB, the expectations placed upon women regarding traditional gender roles remained unchanged within their families. They were still expected to fulfill tasks such as cooking, cleaning, preparing children for school, taking care of the elderly and small children, and providing special care for their husbands. Furthermore, these women were also expected to continue working and making financial contributions to their families. Despite experiencing fatigue, exhaustion, and an increased physical burden resulting from wage work, illness, and medication, patients within such families continued to carry out their routine household chores. These responsibilities persisted regardless of their physical condition, highlighting the gendered expectations placed upon them. The following interview excerpts highlight the untenable situation these women face on a daily basis:

He [husband] refuses to come near me (*P73-Mubeena, 20 years old, garment factory worker*).

My son has avoided me since I got TB (*P59-Santha, 47 years old, restaurant helper*).

I do not mingle [with people] as before. I am scared of humiliation (*P16-Mala, 42 years old, worked in an incense factory worker*).

I wake up at 6.00 [am]. I have four children. I make breakfast for them. Then I do all of the household work, cleaning, cooking. I will go to the DOTS center after that [to pick up medicine]. I go to work by 9.00 [am]. I come back at 7.00 [pm]. Then I eat food and take my tablets (*P55-Manjula, 41 years old, garment factory worker*).

Another significant sphere of conflict was the workplace, where all research participants reported hostile working conditions. The nature of their work was informal, lacking written contracts, social security entitlements, and job security. With the exception of a few participants employed at places like beauty salons, *anganwadis* [government run kindergartens for poor children], and households, the majority of workplaces were marked by physically hazardous environments with poor ventilation, sanitation, and resting facilities as well as dust and fumes. One participant highlighted the ongoing physical symptoms and challenges faced by TB patients in managing their health while balancing their work responsibilities:

There is dust in my work area. I feel that it affects my health. I feel my health will get affected due to work as I am restless and weak, I can't work comfortably. Masks are provided so I use masks at work. The lump in my throat [resulting from TB] has not reduced [in size], it still has pus in it. I bandage it on a daily basis (*P2-Kala, 38 years old, garment factory worker*).

The work environments in which the participants were employed, such as small enterprises like retail shops, hair cutting salons, street vending, and home-based production units, were characterized by informal or non-existent employment relations. Factories, where some of the participants worked, predominantly employed casual workers who were hired through intermediary job contractors. In these settings, the organization of work makes it challenging to establish clear employer–employee relations, thereby allowing employers to circumvent labor laws (Hyde et al., 2020) and evade their legal obligations. These work settings, particularly factories, adhered to a stringent work organization that required employees to comply with

strictly defined deliverables, meet daily targets, and adhere to stipulated working hours. The spheres of work and treatment often conflicted for these individuals, resulting in poor compliance with their TB treatment since regular DOTS visits and taking medicines on time were not possible. Furthermore, the considerable distance between the patients' workplaces and the DOTS centers posed a significant barrier to accessing treatment for some patients. Rajitha, highlighting the difficulties faced by TB patients in managing their treatment alongside their work responsibilities, stated:

The work times clash with the treatment times and so I struggle to get my medicine. Since the employers don't give me time off, it is difficult to reach the DOTS center on time. Commuting to and from the workplace to the DOTS center is also tiring and difficult to manage (*P30-Rajitha, 27 years old, garment factory worker*)

For Dhanalakshmi:

Work prevents me from getting proper treatment. It is difficult to take medicine while working (*P61-Dhanalakshmi, 30 years old, glass factory worker*)

The everyday life of a female TB patient from a lower socio-economic background, living in the peripheries of the city, and engaged in informal work arrangements is marked by a constant negotiation among the spheres of family, treatment, and work. These women experienced debilitating symptoms of the disease while simultaneously coping with the burdensome tasks of household work. On one hand, they grappled with the physical and emotional toll of their illness, and on the other hand, they faced the constant worry of potentially losing their employment and sliding back into poverty. They confronted the unfavorable odds of all of these spheres at the same time.

4 Trudging Through Conflicting Spheres: Everyday Travel of Female Patient-Workers

Travel played an integral role as an indispensable everyday event that interconnected the spheres of work, treatment, and family and social life for the patients. Hence, factors such as travel distance, service availability, schedules, transportation types and modes, and affordability held considerable significance for the patients in reconciling these spheres. Our research has identified three major travel patterns among working female patients. First, there are patients who reside in the outskirts of the city without first-mile connectivity. Second, there are patients who work in places that adhere to strict worker timelines, such as retail shops and factories. Finally, there are patients who have relatively more control over their time management, such as those who are self-employed or work as domestic help.

Patients residing in the outskirts of the city often lacked access to bus services or any other suitable mode of transportations near their homes. As a result, they walked to the nearest public transportation service (see Fig. 1). The bus schedules also posed a significant concern for these patients, as the service was infrequent and unreliable.

This inconsistency in bus schedules often disrupted their daily household activities’ rhythm, sleep patterns, and eating habits. Each day started in anticipation of a possible bus cancellation or delay. Additionally, these patients often had to change buses and rely on multiple routes to reach their workplace. Due to the limited availability of public bus services between their places of residence and work, these patients often prioritized reaching their workplace first over visiting DOTS centers. In order to accommodate their work schedules, these patients made their DOTS center visits during their lunch breaks. To ensure they could return to work on time, they hired auto-rickshaws which significantly increased their travel costs and burdened them financially. Furthermore, the participants revealed that travel to DOTS centers, in addition to their regular commute to work and back home—which included walking and multiple bus journeys—increased their fatigue.

Patients who worked in places where employees are expected to meet specific deliverables or targets within predetermined timeframes had less control and so faced challenges in meeting the requirements of both work and treatment. These work settings predominantly included factories, retail shops, beauty salons, restaurants, and hospitals. Visiting DOTS centers on work days posed a significant source of stress for these patients, as they were constantly worried about meeting the scheduling requirements of both places. For the majority of these workers, the primary travel obstacle they encountered was the lack of first-mile connectivity. This meant that they had to walk long distances to access motorized transportation options. During

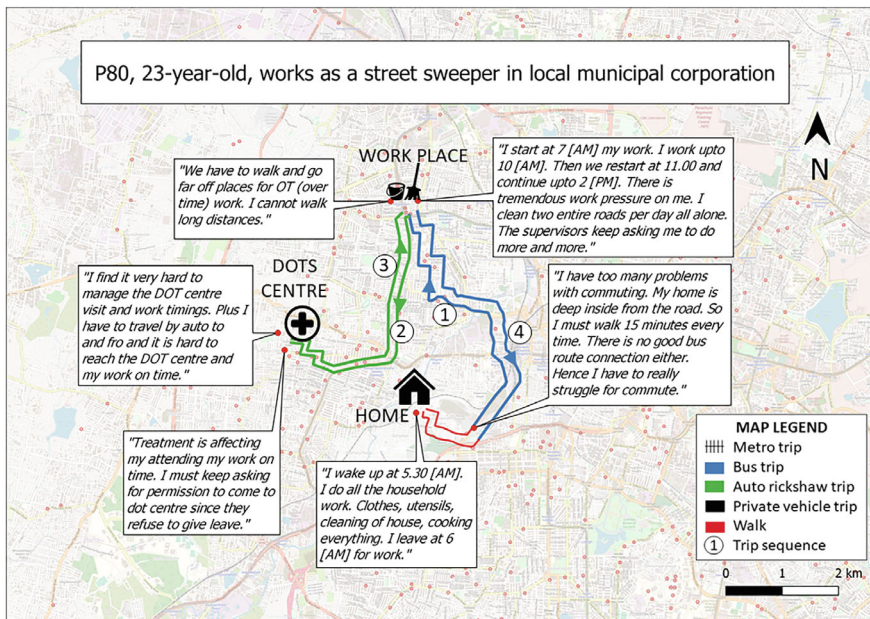


Fig. 1 Travel map of a female patient from the city’s outskirts (Source In-depth interview with a female tuberculosis patient)

the interviews, it became evident that the prolonged walks added to the exhaustion experienced by the participants who were already physically weakened because of their TB infection. Hiring a taxi would considerably increase their travel expenses, leaving them no option but to walk. This was highlighted by one of the participants who worked in a factory, who explained:

I wake up at 4 or 5 am, sometimes I get up to cook food, wash dishes, by 7.30 I walk about 4 kms to work. I am very tired from commuting; I walk as I cannot afford the auto fares. Before I never felt tired from walking but after these symptoms started, I feel weaker and tired. [P12-Jyothi, 33 years old, clinic helper]

We traced the everyday travel map of a patient who worked in a retail shop located within a shopping mall in the city. The shop followed a strict work schedule, which added further constraints to the patient's daily routine (see Fig. 2). The daily travel of the respondent entailed an initial walk from her place of residence to the metro rail station. From there, she traveled 30 min by rail and then walked again to her workplace. Once there, she worked—standing up—for nearly 10 h. During her lunch break, the respondent would visit the DOTS center, which was located far from the place of work. To ensure she could return to work on time, she would hire an auto-rickshaw, which she found expensive. The increased physical exhaustion resulting from the demanding travel routine often made it difficult for patients to effectively balance the spheres of work, life, and treatment. As a consequence, this patient eventually found it challenging to continue employment and made the difficult decision to quit her job.

Some participants also shared the fear of stigmatization which compelled them to choose DOTS centers that were located far from their residences and workplaces. This added to their travel time, exacerbating problems related to fatigue, stress, and increased expenditure. The need to maintain secrecy about their TB condition further added an additional burden when it came to quick and discreet journeys. However, due to limited transportation budgets, fulfilling this need was often unviable for the participants. To cope with these challenges, participants either reduced their number of visits to the medical facility or used proxy travelers to collect medicines on their behalf. One participant shared how she adjusted her schedule to balance her treatment needs:

I visit the DOTS center on weekends [P52-Uma, 22-year-old data entry operator].

Geeta reported that she relies on her mother to pick up her medicine:

Going to the DOTS center on work days is a problem since I never get leave. So, I have to send my mother who goes and collects the medicine for me [P43-Geeta, 20-year-old office helper].

Participants with flexible work schedules were comparatively better positioned to use convenient and affordable modes of travel to reach their workplaces and treatment facilities, which helped them to reduce work–treatment conflicts. This group of participants consisted of individuals who were self-employed, such as street vendors as well as domestic workers and a few piece-rate workers engaged in activities like

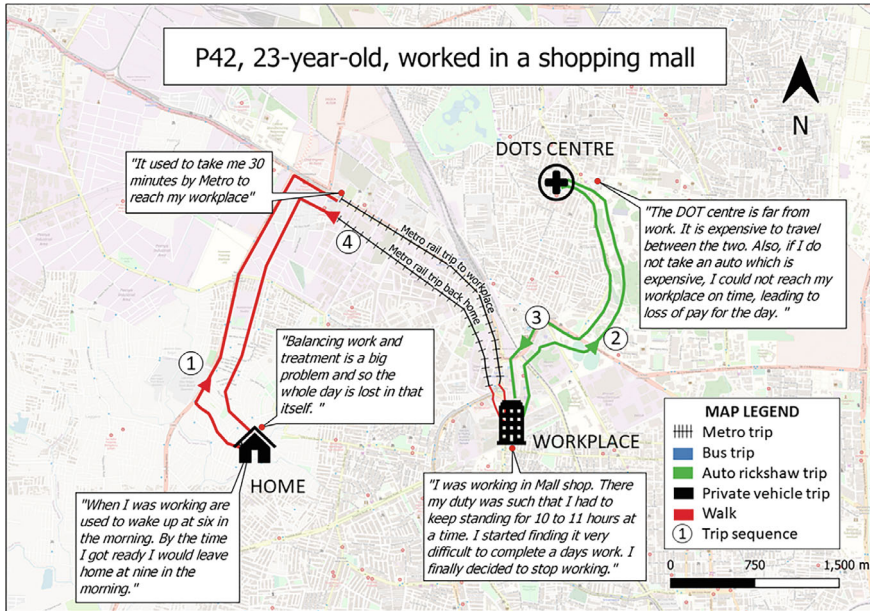


Fig. 2 Travel map of a female patient with a stringent work schedule (Source In-depth interview of a female TB patient)

making incense sticks. The travel map of a respondent who worked as a domestic helper is presented in Fig. 3. As evident from Fig. 3, the proximity to the DOTS center and use of public transportation to commute to work helped the patients reduce the financial burden of travel. They experienced less conflict in managing work and treatment as they had the flexibility to start work later or even take days off for medical care. However, it is important to note that occupations such as domestic help and street vending were characterized by varying levels of stability and uncertainty, and participants engaged in these occupations had to undertake multiple jobs in order to make a living.

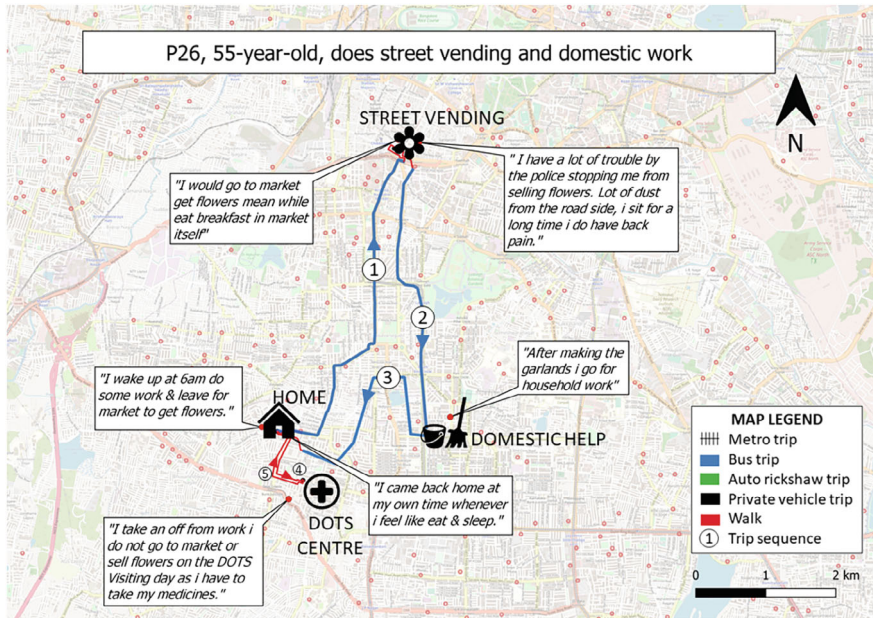


Fig. 3 Travel map of patients with flexible work schedules (Source In-depth interview with a female tuberculosis patient)

5 Conclusion

Harvey (2003) elucidated the relationship between capitalistic accumulation processes and the disenfranchisement of economically disadvantaged populations in cities. The present study highlights that limited access to transportation services, which hinders productive labor market participation and healthcare accessibility, is an additional manifestation of the dispossession experienced by economically disadvantaged individuals in the city. This phenomenon occurs at two levels. First, it is perpetuated by transportation policies that adhere to neoliberal values of privatization and cost recovery, resulting in transportation facilities that are less affordable for the poor. Second, it is exacerbated by the peripheralization of impoverished communities as part of the neoliberal urbanization process, which effectively excludes them from the city's transportation networks and restricts their access to essential services.

The study examined the gender intersections of peripheralization processes and their consequences for access to transportation services. The study revealed that the existing transportation infrastructure was inadequate in addressing the specific needs of women residing in the periphery, who often had multiple responsibilities and faced vulnerabilities. Consequently, women have faced prolonged travel times and heightened costs while accessing labor market and health services. Moreover, travel further exacerbated the burden of informal labor and treatment seeking. The urban poor, especially women in cities like Bengaluru, are concentrated in the informal sectors,

which are characterized by precarious work conditions (George & Sinha, 2017). The nature of work and informality significantly influenced their travel decisions. Stringent work schedules and tight labor control strategies are common in informal work environments, which made commuting to work and seeking treatment especially challenging. For instance, the participants had little autonomy to negotiate favorable conditions both at their workplaces and healthcare facilities, which would have made their journeys less stressful and more affordable. The majority of women employed in low-income jobs depended on private mini bus services as their primary mode of transportation to the workplace, which involved walking the first and last miles. Low-wage factory workers had limited agency and control over their time management. The physical debility caused by TB made even short walking distances tedious and challenging, thereby impacting their ability to access first-and-last-mile connectivity to public transportation services. Participants reported that they experienced fatigue and stress due to the combined challenges of TB; work; and haphazard, uncertain, and often expensive travel conditions. As a consequence, the participants experienced difficulties in adhering to their treatment plans. Existing evidence supports the notion that various social, economic, and cultural factors, including constraints associated with work status, act as barriers to the compliance with the DOTS regimen (Deshmukh et al., 2018). The present study found that the coping strategies employed by the participants, such as avoiding DOTS visits, relying on proxy travelers, and procuring medicine for an extended period, were adopted as a means to alleviate the burden of travel. The DOTS treatment regimen is designed to ensure the supervised administration of medication to prevent treatment defaults and ensure regular follow-up examinations for patients.

The study revealed that inadequate access to transportation posed a significant barrier for women laborers in effectively balancing their work, personal life, and healthcare needs. These female patients, especially when married, faced challenges in balancing family life and maintaining relationships. Family members, particularly spouses and children, were found to perpetuate stigma. Instead of providing support, they avoided the patients behaved unsympathetically towards them. Fatigue and limited time availability due to work, treatment, and travel requirements, and the fear of stigmatization collectively led some women to withdraw socially. The management of household responsibilities, coupled with the demands of travel from and to the DOTS center and work, created conflicting priorities for the participants. Due to limited resources for mobility, women from low socio-economic strata often encountered insecure livelihoods and inaccessible health care, or a combination of both, thus pushing them into health-poverty traps. Women who lacked family and spousal support struggled to manage household responsibilities, accessing healthcare services, and maintaining their workspace. Additionally, these women experienced a decline in earnings as they struggled to meet work targets and had to leave work without receiving wages. The combination of multiple responsibilities, inflexible working conditions, and inaccessible transportation systems (in terms of affordability and availability) resulted in arduous travel experiences, leading to a few participants withdrawing from work. However, quitting their jobs was not a viable option for all

participants, particularly for those who were the sole earners for their families. They feared that leaving their jobs could push them into poverty.

In conclusion, the everyday experiences and realities of female working patients in cities of the Global South, like Bengaluru, are deeply embedded within a context of interplay of exclusion, patriarchy, poverty, and informality. Travel, with the limited and often challenging options available within these complex embeddings, does not provide an enabling experience for them as they strive to balance their work, personal life, and medical treatment. Conversely, travel conflicts with these spheres and gives rise to numerous challenges, such as difficulties in meeting work targets; lost work days and earnings; increased fatigue and mental stress; compromised treatment schedules; and disruptions in intimate, family, and social life. The everyday realities and nuanced experiences of female patients' life world are often inadequately addressed in existing policies and programs aimed at improving access to travel, health care, and the labor market. For instance, India has committed to SDG3—a Sustainable Development Goal of the United Nations—to end the epidemics of AIDS, tuberculosis, malaria, and other communicable diseases by 2030. India is similarly committed to SDG11, the goal of making cities safe, inclusive, resilient, and sustainable. The study shows that there is also lack of attention paid to the travel barriers of patients working in informal arrangements within India's national tuberculosis elimination program. Similarly, the challenges faced by poor and vulnerable communities living in urban ghettos in accessing the labor market and health services are often overlooked in ambitious city development programs such as the "smart city project" in India, which aim to fulfill SDG11 (HRLN, 2018). The study highlights that equitable access to transportation is a crucial component in guaranteeing the rights of the poor to the city. It emphasizes the pressing need to initiate discussions on the importance of inclusive and affordable transportation for vulnerable populations in the cities of the Global South.

Funding The chapter is based on the study funded by the Indian Council of Medical Research (ICMR), New Delhi, titled "Tuberculosis and the Social Construction of Women's Employability: a Study of women with History/Symptoms of Tuberculosis in Bangalore City."

Ethical Statement The study was approved by the ethics committee of the Institute for Social and Economic Change, Bangalore in a meeting held on March 23, 2017.

Annex

Table 1 Sample profile

	No.	Respondent code
<i>Age</i>		
15–24	28	P3, P8, P9, P14, P15, P21, P23, P31, P36, P42–P44, P47, P50–P54, P56, P60, P66, P68, P69, P73, P75, P76, P78, P80
25–34	27	P1, P4, P7, P11–P13, P17, P19, P22–P24, P27–P30, P33–P35, P49, P57, P61–P63, P65, P70–P72
35–44	19	P2, P5, P6, P10, P16, P20, P25, P32, P37, P39–P41, P45, P46, P4, P55, P58, P74, P79
45–54	3	P38, P64, P67
55–64	3	P26, P47, P77
<i>Education</i>		
Unlettered	10	P1, P7, P26, P33, P37, P38, P59, P74, P75, P77
Primary	9	P13, P19, P21, P39, P40, P41, P45, P57, P78
Secondary	31	P2–P6, P9–P12, P16, P20, P23, P24, P28, P30, P32, P36, P44, P47, P49, P50, P51, P54–P56, P60, P67–P69, P73, P79
Higher secondary	13	P14, P15, P17, P18, P29, P31, P34, P43, P46, P58, P61, P70, P76
Graduation and above	17	P8, P22, P25, P27, P35, P42, P48, P52, P53, P62–P66, P71, P72, P80
<i>Nature of work</i>		
Personal care/domestic work	18	P24, P20, P39, P4, P21, P41, P57, P45, P75, P1, P37, P38, P40, P28, P7, P67, P5, P23
Self-employed	5	P26, P77, P22, P80, P35
Employed in factories	25	P64, P2, P15, P18, P30, P28, P33, P50–P52, P54–P56, P61, P66, P7, P69, P73, P78, P31, P32, P16, P14, P68, P47
Service sector	26	P49, P12, P8–P10, P29, P42–P44, P48, P59, P62, P70, P72, P76, P79, P11, P60, P36, P19, P27, P3, P17, P53, P58, P34
Professionals	6	P65, P46, P63, P71, P6, P25
<i>Disease details</i>		
Pulmonary TB	35	P1, P6–P8, P10, P15, P18, P21, P22, P26, P28, P31, P32, P35, P40, P41, P43, P46, P49–P51, P54, P56, P58, P59, P61, P63, P68–P70, P72, P74, P76, P77, P79
Extra-pulmonary TB	45	P2–P5, P9, P11–P14, P16–17, P19–P20, P23–P25, P27, P29–P30, P33, P34, P36–P39, P42, P44–P45, P47–P48, P52–P53, P57, P60, P62, P64–P67, P71, P73, P75, P78, P80

References

- Deshmukh, R. D., Dhande, D. J., Sachdeva, K. S., Sreenivas, A. N., Kumar, A. M., & Parmar, M. (2018). Social support a key factor for adherence to multidrug-resistant tuberculosis treatment. *Indian Journal of Tuberculosis*, 65(1), 41–47.
- Fletcher, E., Pande, R., & Moore, C. M. T. (2017). *Women and work in India: Descriptive evidence and a review of potential policies*. HKS Working Paper No. RWP18-004.
- George, S., & Sinha, S. (eds.). (2017). *Redefined labour spaces: Organising workers in post-Liberalised India*. Taylor & Francis.
- Harvey, D. (2003). The right to the city. *International Journal of Urban and Regional Research*, 27(4), 939–941.
- Harvey, D. (n.d). *The right to the city*. Retrieved September 27, 2021, from <https://davidharvey.org/media/righttothecity.pdf>
- HRLN. (2018). *India's smart city mission: Smart for Whom? Cities for Whom?* Housing and Land Rights Network.
- Hyde, M., George, S., & Kumar, V. (2020). Trends in work and employment in rapidly developing countries. *Handbook of Disability, Work and Health*, 33–52.
- Lucas, K. (2012). Transport and social exclusion: Where are we now? *Transport Policy*, 20, 105–113.
- Webber, S. C., Porter, M. M., & Menec, V. H. (2010). Mobility in older adults: A comprehensive framework. *The Gerontologist*, 50(4), 443–450.

Open Access This chapter is licensed under the terms of the Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>), which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license and indicate if changes were made.

The images or other third party material in this chapter are included in the chapter's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the chapter's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.

