

# Indigenous Women Caregivers

Intersections of Gender and Occupational Health in Panna



**DHAATRI**

**A Resource Centre for Women and Children**



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About Dhaatri:

An NGO working for the rights of women and children in India and the protection of the ecological resources and women's knowledge practices. We are a platform to amplify the voices of women, their struggles and demands for gender equality and environmental justice.

# **Indigenous Women Caregivers**

Intersections of Gender and Occupational Health in Panna

*Report Dedicated to the Caregivers of Panna*

# CONTENTS

Executive Summary .....	05
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## ***Section I - Tuberculosis, Silicosis and the Tribal Community in India***

Introduction - Why This Report? .....	14
Prevalence of Tuberculosis and Silicosis .....	16
Systemic Problems at National Level .....	20
A Gendered Perspective - Global and National Scenario .....	31

## ***Section II - Stories from the Ground - Caregivers of Panna***

Introduction and Field Study Methodology .....	40
Panna - The Study Area .....	42
Silicosis and Tuberculosis Affected Villages .....	45
Widows and Caregivers of Panna: Personal Narratives .....	53

## ***Section III - Key Concerns***

Findings from the Field .....	71
Key Concerns and Recommendations .....	91
Glossary of Terms .....	100
References and Further Readings .....	101

## Executive Summary

This report is an outcome of fieldwork in Panna district of Madhya Pradesh and our work with women and children in some of the Panna Tiger Reserve affected indigenous/tribal villages. The report highlights the crisis of Tuberculosis (TB) and Silicosis among these communities and the large-scale devastation on tribal families that these combined diseases bring to them.



***Tuberculosis and Silicosis, as co-morbidities or sometimes misdiagnosed as one for the other, have persisted as a combined fatality among many tribal groups in India. While Tuberculosis is recognised as a public health concern and has a national programme for prevention and eradication, Silicosis which is considered chronic and progressively incurable, has remained largely unaddressed. States like Madhya Pradesh have still not formulated a policy for prevention and rehabilitation with regard to Silicosis, thus posing a serious lapse in legal relief and rehabilitation to victims.***

***This report brings focus to the condition of women as caregivers to patients of Silicosis and TB, while being patients themselves.***



Their social and economic conditions of poverty and ill health, driven in large measure by challenges like conservation programmes, mine labour, resource and livelihood losses, which are not merely medical in nature, reflect the need for addressing this severe and crippling crisis from a deeper understanding of resource politics.

Findings of this report and secondary research indicate that Tribal women and children as patients and caregivers bear a higher share of the social and financial burden of Tuberculosis and Silicosis. While data shows that men have high prevalence rates as compared to women, ground realities presented in this report highlight several constraints that prevent women from getting diagnosed and treated or being included in relief and rehabilitation policies. This report is intended to strengthen ongoing policy level dialogues and implementation strategies to address the public health concerns surrounding TB and Silicosis, from a gendered perspective as well as from an interdisciplinary understanding of causes and interlinkages. We hope that it evokes the urgent sensitivity and serious reflections on the 'Detect-Treat-Prevent-Build' of the NSP 2017-2025, for a more intersectoral and multi-dimensional approach to the state health policy and interventions, which the victims and caregivers rightfully deserve.

This report therefore, focuses on the personal narratives of Gond Women in Panna, as Caregivers and patients of these two dreaded diseases, and through these narratives, connect the existing body of research and demands of several academic, civil society and community groups, for redress and preventive actions. Of particular concern is the emerging conflicts around climate change actions and business accountability in the informal supply chain processes where larger debates around due diligence towards work-

ers, occupational health and safety, environmental accountability and just transition alternatives may be neglecting this important constituency of women and children.

We provide the multiple challenges faced by affected communities on the ground through this very micro level assessment of the problems gathered from the voices of women. Starting from the spillover impacts of relocation and dispossession from their lands and forest resources, and the constant necessity for migration and strenuous mine labour that is informal and unregulated, the women shared their increase in burden of work for gathering food, firewood, water while traveling longer distances for wage labour as livelihood opportunities are not available locally. With most households being widow-headed or with women and children being the primary income earners as majority of the men-

folk are suffering from either TB or Silicosis or both, the physical, emotional and financial distress along with crippling debts for medical expenses incurred, has left most families falling apart and on the brink of starvation. Loss of land and forests have led to large sections of tribal people shifting from cultivation and forestry to daily wage and informal labour in hazardous industries, with negative impacts on their livelihoods, food security, resource access and entitlements.

Further, lack of due diligence in the delivery of institutional obligations of rehabilitation after eviction from the Panna Tiger Reserve, has led to mass seasonal migration through intergenerational cycles of hazardous mine labour. Majority of Gond families have worked or are still working as informal mine labour seasonally, with no occupational safety measures or even a registered



*A woman serves food to her TB-diagnosed daughter in Umravan village, Panna*

employment identity. Majority of workers were found to be suffering from ill health and have developed drug resistance after multiple rounds of TB medication that were sporadically used, due to several constraints like migration, misdiagnosis or non-diagnosis for Silicosis, malnutrition induced lack of physical ability to withstand strong medications, delays in availability of drugs, financial distress, lack of information or motivation on following TB protocols, and many other real life problems. Further, the vulnerability of women and children to the contagion of TB was starkly visible with the poor living conditions and lack of basic amenities in addition to the highly malnourished condition that make them susceptible to all infections. Of all the TB and Silicosis cases traced in this study, it was found that active case finding and tracking and last mile linkages for case detection, treatment and prevention were not happening, especially with drug resistant patients receiving little or no motivation from the state structures. These services were provided by our own barefoot health volunteers, in the absence of whom, patients lived and died unattended. The state-wise TB notification rates for 2022 which provide the basis for intervention may be far from accurate, going by the high incidence of TB and Silico-TB traced in this small sample size in the study villages which is validated by the NATBPS 2019-21 findings “that up to 64% of those with presumptive TB symptoms or signs in the general population did not seek

care”. So is the need for review of the End TB strategy and its ‘catastrophic costs’ assessment procedures where huge household expenditures were found from the case studies of affected families in these villages.

Of foremost concern is the burden of Caregiving that falls on women and even little children which leaves them with little scope for getting themselves treated or cared for, even when they are patients and suffer from ill health. Caregiving in such challenging conditions of lack of amenities and distress of livelihood caused by resource dispossession have created severe forms of workload increase for women, as unpaid caregiving work leaves them with limited scope for seeking paid work.

Marginalised by social and economic hierarchies of dominant non-tribal castes and unsympathetic state structures, the Gonds are the last to receive benefits of employment guarantee like the MGNREGS, welfare schemes or land entitlements. The non-implementation of constitutional mandates like the Forest Rights Act, mining and occupational health and safety laws, the Right to Education Act or the DMF provisions of the MMDR Act are evident in Panna, especially with regard to the Gonds. Both public health infrastructure and other state obligations appear poor in their outreach for these communities, and the extreme conditions of poverty and distress migration leaves the Gonds with

“



***My husband worked in stone mines for 15 years. Eight years back his health started to deteriorate and he was diagnosed with TB last year. Since then he is finding it difficult to work. Hence I go to Panna for labour work. I also have to take care of all the household work with my daughter.***

***- Badi Bahu, Madaiyan***



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little time to pursue getting their entitlements from local authorities.

While the public health facilities are grossly inadequate, where even diagnosis for Silicosis was so far not available at the PHC, the Silicosis affected had no way of providing evidence of their disease in order to apply for relief and rehabilitation. Despite the new changes in PHC infrastructure to some extent where diagnosis is available, the state has no policy for prevention and rehabilitation. Mere certificates as proof have been ineffective in getting help for these families. There are several lacunae in community outreach and support from the public health system which is also evident from several larger secondary reports on the public health system in Madhya Pradesh.

Concurrently, the critical challenges are beyond merely the domain of medicine and public health. The stories from the ground bring strong interlinkages to the situation of

poverty and ill health to several other systemic gaps interdepartmentally and at policy levels of development economics. An urgent and deeper review of the very nature of conservation and extraction politics is required, where the rich biodiversity and wildlife of Panna and the equally rich traditional knowledge of the Gonds in being custodians of their biodiversity have to be recognised for any sustainable development roadmaps to be chalked out. The distress of the Gonds today needs urgent redress on multiple fronts. The new challenges to Panna's eco-systems in the form of expanding formal and informal mines, climate action programmes like afforestation plantations, urbanisation in the name of wildlife tourism and other infrastructure projects pose more serious threats to the forests of Panna but the Gond women's firewood and NTFP collection and the very presence of tribals in the forest is perceived as being serious threats to the ecosystem.

## Key Concerns and Recommendations

These realities demand for legal interventions and corrective measures for immediate relief and long term preventive and rehabilitation actions on some of the critical areas such as:

Urgent assessment of TB prevalence among tribal groups both in scheduled and non scheduled areas and proper enumeration of patients, acuteness, resistance rates, availability of drugs, laboratories, human resources, community outreach systems and other medical facilities in the tribal area PHCs. The National TB Mission lays out standards and protocols which need to be reviewed and intensified as case identification and follow-up strategies need to be specifically redesigned for these remote areas. Although the NTEP lays out a Gender Responsive Approach and Framework and collaborative model with in-

tensive case finding, training of ground personnel and linkages with medical ethics and protocols to be strictly followed in discriminating TB with Silico tuberculosis and Silicosis to avoid wrongful medication and further harm to patients and to provide appropriate medical and non-medical relief interventions. In this regard proper technical training and screening facilities need to be created from PHC to community level, where ASHA workers and sub centres are trained and motivated in order to effectively tackle TB eradication goals. Special funds and focus is required for creating barefoot teams of Community Health Volunteers as last mile public health providers. As laid out under the NHM, setting up grievance redress desks at the PHC and counselling support both for patients and caregivers, has to be seriously considered for TB and Silicosis affected families with trained



personnel, time-bound outreach and linkages to other social security schemes.

Silicosis prevention and rehabilitation policy for Madhya Pradesh needs to be urgently approved by the state government. State policies should include, apart from several basic amenities for the rehabilitation of affected families, pensions not only for survivors but for caregivers during and after the life of patients as their paid work is drastically affected by time spent in caregiving and loss of opportunities and death of their primary earning member.

Silicosis should be brought within the purview of public health and given the attention of critical diseases like HIV/AIDS, cancer and other terminal illnesses under the National Health Mission with a national programme for identification, treatment support and palliative care. Public health infrastructure at

PHC and sub centre level to be upgraded with facilities for diagnosis, certification and primary care support. Patients certified by PHC should become eligible for immediate monetary and medical relief without the complex processes of proof of employment. In DMF districts, the PHC in tribal areas should have palliative care wards where Silicosis victims in need of emergency and palliative care support like oxygen cylinders and other high quality respiratory and life saving equipment and skilled personnel should be available. Regular updates of Silicosis patients from PHCs to be collected and placed in the public domain for transparency and public health accountability.

Gender disaggregated and age disaggregated data of informal mine workers has to be collected regularly by the labour department and put in the public domain. The mines and labour departments have to implement



*A stone mine in Panna district*



***My husband and I suffer from TB. Since we were displaced from Umrahan, we no longer have access to Mahua or any other forest produce. Both of us have to travel to Panna or some nearby towns to find work. Because of our illness we can't travel far. But we have to keep working or we won't be able to take care of our children or our own health.***

***- Geeta Bai, Hirapur***



these in a time bound, digitised and transparent manner and placed in the public domain. Punitive and legal actions have to be laid out clearly for non-disclosure and non-compliance.

As time and again brought out by CAG audits, there is no proper assessment of illegal mines, mining leases, monitoring of operating mines by the labour departments and mine closure monitoring to protect the occupational health of workers, labour protocols, periodic reports of inspections conducted mine-wise on mitigative measures, status reports on revenues from mining, royalties, late payment fees, taxes, dead rents, CSR and DMF funds collected, employment registers compared with Shramik portal data and such other information. The Ministry of Mines has to provide action taken reports on their responses to the CAG audits and on the utilisation of DMF funds and place these in the public domain.

Migration is a major concern for occupational safety of workers, their access to social security schemes and access to basic public health and education entitlements for themselves and their families. Shramik portal should allow for registration of mine workers and migrant workers, irrespective of proof of place of work or employment registration, based on their basic identification

documents like ration card, Aadhar card. Workers should have the option of entering their changes in type of work, place of work, period of work and other details in the Shramik portal so that tracking of seasonal migration, flexible eligibility and claims for labour relief measures under various mineral welfare, construction worker and other labour welfare funds, health insurance and free healthcare facilities are accessible to them irrespective of the state or district of work.

There are several labour welfare schemes and special purpose funds dedicated for various categories of workers, especially mine workers. Yet, informal workers suffer from inaccessibility to any monetary, medical or non-medical support with long term impacts on their families when they meet with accidents, injuries, occupational health issues like Silicosis and Tuberculosis. Thus, although financial resources are available and there is adequate potential for resource allocations under welfare funds, the non-compliance with revenue collection protocols, lack of information on fund utilisation and application procedures and diversion of funds collected/available for workers to other general purpose expenditures, is leading to breach in accountability towards informal workers. The Ministry of Labour at the Centre and at the state level should put in the public domain and display in their websites, the ex-

penditures and worker details for the various mineral and labour welfare schemes and informal mine workers should receive benefits under the ESI and other special purpose funds. Any diversion of funds or non-utilisation of funds meant for workers has to be reallocated into the labour welfare funds for subsequent years and strictly utilised for the purposes for which these funds have been created. Utilisation of these funds should be annually reported and placed in the public domain and online facilities for availing of these funds should be included as part of the digital India programme.

Special purpose funds like the District Mineral Funds, across the country, are not being reported or utilised as per PMKKKY guidelines with proper assessment of directly and indirectly affected people, micro planning and five year planning and inclusion of affected communities and workers. In Madhya Pradesh, this lapse is very stark. Most districts, including Panna, do not have a website where DMF annual plans or reports

and other information are disclosed. If implemented, they are redirected to general purpose expenditures within the district while areas where environmental damages directly induced by mining and local communities suffering from multiple impacts, remain unredressed. This defeats the purpose of mine area restoration and mining affected communities' rehabilitation. Despite Panna having several small mines (licensed and unlicensed) and the country's largest diamond producing mine next to which the villages covered in this report are located, the Gonds remain malnourished, poor and suffering from ill health and lack of livelihood opportunities. The area holds vast potential for several regenerative and just transition activities by linking the DMF funds with other social security schemes like the MGNREGS (particularly as negligible numbers of Gonds have been able to access it) where employment guarantee could reduce seasonal migration and starvation. The Silicosis rehabilitation welfare schemes should be linked to the DMF funds so that affected families get



*The decaying carcass of a cow killed by wild animals near Umravan village, Panna*

medical relief, pensions for patients and caregivers, local livelihoods, seasonal hostels for children of migrant workers, rehabilitation of child labour, home based micro enterprises and livelihoods training support for caregivers especially on forest based products, clean energy stoves, local alternate electricity and energy generation for agricultural activities, lighting, irrigation and drinking water, toilets with water supply, community health volunteers for TB and Silicosis patients, compensation and protective measures for wildlife attacks and several other site specific needs.

In Panna, the villages affected by relocation and dispossession from their lands and forest resources are also villages which have a high incidence of Silicosis and Tuberculosis. They have to be assessed through an intensive field investigation conducted by the National Commission for Scheduled Tribes and the Ministry of Tribal Affairs for implementing a comprehensive rehabilitation support programme. Pending claims of compensation, settlement of rights under the FRA, settlement of grievances of Gonds related to encroachments where relocation sites do not have proper ownership titles to houses and lands, proper land development for cultivation and forestry where lands were given as compensation, and other basic facilities like

primary schools, anganwadis, drinking water, housing, toilets, ration cards, pensions, and a horde of other entitlements that remain pending need to be urgently implemented. The state tribal welfare department needs to play a more active role in extending its programmes and governance support to these tribal pockets which are neglected due to being outside the fifth schedule areas.

The conservation model in Panna, as elsewhere, has caused great suffering to the Gonds while compromising on diversion of forest lands for other non-forestry commercial and development projects. New forms of restrictions like fortress plantations under climate action programmes are further restricting the entry of tribals for their basic food, firewood, NTFP and further causing distress to caregivers and patients. The loss of cattle to wildlife attacks has become a huge burden on these families already staggering under debts for health expenses. Community inclusive and conservation methods of eco-systems protection and regeneration without further diverting forest lands for non-forest purposes would be a more sustainable form of promoting the co-existence of tribals who have traditional nature based conservation practices and in allowing wildlife to have sufficient corridor space for their movements.



*A TB patient works in his field in Madaiyan village*

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**Section I**  
**Tuberculosis, Silicosis and**  
**the Tribal Community in India**



## 1. Introduction - Why This Report

India's tribal communities, accounting for 8.6 per cent of the population and living in rural and forest areas, are marginalised on most development indicators and face a host of structural inequalities, with access to health-care being among the biggest. While tribal communities in India are more susceptible to pneumoconiosis and malnutrition, those working as labourers or residing in the vicinity of developmental projects like mining are at a higher risk of contracting such diseases. According to the World Health Organisation, "the conditions in which people are born, grow, work, live, and age.... These circumstances are shaped by the distribution of money, power and resources at global, national and local levels." TB and Silicosis have persisted as co-fatalities among many tribal groups, often overlapping with areas that have mining operations or other development projects where constitutional lapses and lack of access to remedies see local communities suffering from multiple challenges.



***Working in mines often involves exposure to large quantities of mineral dust that puts the workers at risk of contracting lung infections with varied levels of severity.***



These diseases are very closely associated with each other and can be easily misdiagnosed or wrongfully treated, causing greater harm and suffering to the patients, if adequate resources are not employed in the



*Workers at a stone mine in Panna district*

detection and surveillance of occupational health and safety.

While certain types of pneumoconiosis like Tuberculosis are officially recognised and have dedicated Detection, Prevention, Control and Rehabilitation policies, other lung diseases like Silicosis, Silico-Tuberculosis and related ailments remain unaddressed due to several systemic, political and public health lapses. The main challenge of eliminating and preventing Silicosis in India is in the informal, unregulated sectors of industry which do not fall under the control of statutory tools such as the Factories Act of India (1948). Silicosis-affected workers in the informal sector are not entitled to statutory protection, which would remove them from the hazardous environment, or to rehabilitate, which would enable them to leave the work (Sharma et al 2016). This further complicates the eradication of tuberculosis since other ailments that are closely associated with tuberculosis are being systematically neglected.



***We are concerned with the growing incidence of TB among tribal populations and the invisible suffering due to Silicosis that brings no relief to affected workers. The Ministry of Tribal Affairs and the Central TB Division of the Ministry of Health and Family Welfare have now zeroed in on 75 tribal districts, where focused interventions will be run over the next few months with the aim to make them TB-free. We are concerned that some of the tribal pockets having high concentrations of TB have been missed out of this important programme and therefore, we hope that this study will bring attention to these affected communities for more inclusive eradication efforts.***

***Even while the national government has recognised the urgency of addressing TB through the Ashwasan programme (TB Free Tribal India), the intent to address Silicosis and bring state accountability to the agonising disease among many poor communities still suffers from acute neglect at the national level and fails to deliver at state levels.***



This report is an outcome of a field study of Silicosis and Tuberculosis among Adivasis in Panna district of Madhya Pradesh where we are working with the Gond tribe affected by these comorbidities. As an organisation working with tribal women, our focus has been to understand the gendered impacts of these diseases and to present them from our own field experience of working with the Gond women and from the body of existing research, to reiterate the repeated calls for attention to the plight of these communities, from several civil society, academic and media groups.

The report is presented in two parts - a gendered analysis of the dual diseases at the national level from secondary research, and a field assessment based on fieldwork and case studies with affected communities. This report primarily focuses on the health crisis among STs in mining and forest areas of Panna, Madhya Pradesh, where alienation from their land and natural resources have led to long and vicious cycles of poverty, migration, unsafe work and livelihood insecurity that have further resulted in occupational health problems, child labour, malnutrition, hunger and gender based economic, social and sexual vulnerabilities. Health concerns like

Silicosis and Tuberculosis remain neglected, despite new initiatives launched, like that of the Ashwasan/TB Free Tribal India, the Just Transition frameworks for mining areas and allocation of rehabilitation funds like the District Mineral Funds.

This field study primarily tried to understand the situation of Gond Adivasi Women – as patients and as care-givers. Working closely with the women and their families helped us gather first-hand accounts of their life stories, their daily life struggles, their challenges in accessing public health systems and their journey of engagement with governance bodies for basic entitlements and social security schemes. We hope that, by bringing focus on the invisible lives of these women as forest dwellers, mine workers and as caregivers, we can engage with governance institutions and

policy makers to improve dialogues for systemic and structural obligations on health as well as on the economics of resource utilisation.

The field study corroborates most of the secondary analysis of TB and Silicosis drawn from existing research documents from a gendered perspective as well as from media and NGO reports. New investments and interventions, particularly in the context of climate change, viewed from a gender perspective, bring new challenges than relief to women, spilling over into their health and access to resources vis-a-vis gender equity. One needs to assess sustainable development goals from these lived realities of women's health in the current context of environmental politics and climate change actions.

## 2. Prevalence of Tuberculosis and Silicosis

### TB Prevalence

Tuberculosis (TB) is an infectious disease, caused by a bacterial pathogen, *Mycobacterium tuberculosis*, and is one of the top-ten causes of deaths in humans (about 1.5 million each year) due to a single infectious agent. India contributes almost 30% of the global Tuberculosis (TB) burden with a prevalence rate of 195 per 100,000 population nationally (Mistry et al 2017). Among the tribal communities in India, it is one of the most prevalent diseases. The Tribal people (10.4 Cr, 8.6% of the total population) have a higher prevalence (703 per 100,000) of TB compared to the national average (256 per 100,000). It is reported that 10.4% of all TB-notified patients are from tribal communities (GOI 2022).

The tribal communities who generally live in forests and near mineral operations, are at a

greater risk of being exposed to pollution and environmental degradation that these projects accompany. These factors put them in a disadvantaged position in terms of health, livelihood and their traditional ways of living. Tuberculosis among the tribal community is one such symptom of our developmental model (Kuznet, 1973).

Loss of land and forests have led to large sections of tribal groups shifting from cultivation and forestry to daily wage and informal labour in hazardous industries, with negative impacts on their livelihoods, food security, resource access and entitlements. Further, lack of due diligence in the delivery of institutional obligations of rehabilitation has led to mass seasonal migration through intergenerational cycles of hazardous mine labour and has seriously affected the health



and well-being of Adivasi communities. Mine workers are constantly threatened with contracting TB due to several associated risk factors like poor living and working conditions, migration, air and water pollution, chemical toxicity, malnutrition, high prevalence of HIV and occupational diseases like pneumococcosis. Although TB among miners has been recognized as a public health emergency by researchers globally, it has remained neglected to date in India possibly due to a lack of surveillance data (Husain et al 2022). TB is predominantly a disease of disadvantaged and marginalized groups, particularly the poor and hard-to-reach groups. Frequent movement of the population or migration to another area are known to play a significant role in the spread of this disease. They move to the neighbouring block or even elsewhere to other states in search of employment. They could be contracting the infection from the general population and spreading the infection in the tribal areas on return. (Chamka et al 1996).

Climatic factors such as dew point temperature, relative humidity and atmospheric temperature that affect water droplet formation

contribute to the survival and spread of tuberculosis (TB). A recent study that assessed the health of the villagers in Tamnar block of Raigarh, where there are several coal mines, revealed that nearby mining activities have put “tribal population of Raigarh at increased risk of acute respiratory infection (ARI), tuberculosis, road traffic accident (RTA). Water supply might play a crucial role in the transmission of TB since proper hospital wastewater treatment is a major concern in states like Mizoram in Northeast India. (Sailo et al 2022)

A study from one district in the mountainous border state of Arunachal Pradesh revealed significant variation in the prevalence of use of alcohol and tobacco based on specific tribe membership, in addition to other variables including ethnicity, altitude of residence, occupation, and religion (Chaturvedi and Mahanta, 2004) In addition, other aspects like literacy, socioeconomic status, socio-cultural/mythological beliefs on health, roles of traditional healers in the community, social stigma and gender based discrimination indirectly affect health outcomes in general, and TB infection and transmission, in particular. Several social/personal behaviours the com-



*Men engaged in construction labour in Panna*

munity regularly practices, e.g., open-spitting, sharing of country-made cigarettes wet with saliva, wetting the fingers with saliva for playing cards, etc., can contribute to the easy transmission of tuberculosis in the community. Furthermore, living and sleeping inside a poorly-ventilated single-room house provide conducive situations for transmission of TB

bacterium among family members, and livestock populations as well (ibid). Still more research and exploratory studies are required to understand the interplay of these risk factors, amplifying the tuberculosis burden especially among the PVTGs in tribal areas (Lancet, Tb report 2022).

## Silicosis, Silico-Tuberculosis and its Prevalence

Silicosis is an incurable lung disease caused by inhalation of dust that contains free crystalline silica (International Labour Organisation). Despite all prevention measures, Silicosis still affects tens of millions of individuals who work in dangerous industries. Silicosis is one of the most significant occupational health conditions in the world due to its propensity to result in gradual and permanent physical impairment. A recent media report states that 10 million miners working in the above mentioned sectors are exposed to silica dust. (The Times of India, June 20, 2016). It is also reported that 50 percent of miners are found to be suffering from Silicosis in any given age group. Silicosis is a dreaded disease that is widely affecting the majority of tribal migrant labour or tribal communities who work in the largely informal and illegally operating mines around their habitations. 'The disease is reported from almost all occupations wherever silica dust exposure occurs; however, mining is the most affected industries'. Majority of tribal labour work either in the mining sector, factories or construction industry as informal workers with no work safety, employment guarantee or social security coverage.

The number of persons who die from Silicosis in India is very high going by recurring media and NGO reports, but there are no official statistics available concerning these deaths. It is neither recognised as a public health



***Unlike other diseases, there are no symptoms whatsoever whereby one can come to know about the onslaught of the disease in its early stages.***



concern nor does it receive systemised public health interventions for prevention, treatment and support or of data compilation. It has also been established that there is no medical treatment available for Silicosis, and particularly no public health programmes for the much needed palliative care and support like that of cancer and HIV/AIDs which the National Health Mission covers. Victims are always poor and are left to die a gradual death in extreme agony and suffering.

A large number of workers in India are employed in unorganized small-scale mines or as daily wage labour of large scale mines, exposed to fine dust containing free silica in the range of 70–90% depending on the nature

of stone or other ores extracted. Especially, the working conditions in stone mines are far from satisfactory and rarely comply with health and safety standards. The exposure to silica dust for long duration causes Silicosis and is also known to predispose towards pulmonary tuberculosis, chronic airflow limitation, lung cancer, renal diseases, etc. Studies have shown that the time of exposure to silica dust plays a very important role in the Silicosis prevalence rate (Nandi, Dhatrik and Sarkar 2021), and showed that Silicosis developed even with a working duration of 10 years or less in the case of mines. Sporadic studies conducted in small and unorganized sectors and in mineral processing units especially in sandstone mines and stone processing have reported high prevalence of Silicosis among workers.

Calvert et al. reported that the prevalence of TB has a direct relationship with the con-

centration of free silica dust in the work environment and the risk of TB increased with increased duration of exposure to silica (ibid). Additionally, the study observed that workers developed TB on an average of 7 years after discontinuation of silica exposure. Occurrence of Silicosis is directly related to the degree of exposure to silica dust and the higher and longer the exposure, the more is the risk of developing Silicosis. The study also indicated that the workers are at higher risk of TB even after discontinuation of exposure.

A person is predicted to have Silicosis when it cannot be treated even after completion of TB therapy. After the initial 1–2 months of intensive anti-TB treatment, patients return to dusty work conditions, increasing their exposure to silica dust even further, and the vicious cycle continues, causing them to develop TB again along with having Silicosis. Because exposure to silica dust makes peo-



*A worker breaks stones at a mine in Panna district*

ple susceptible to tuberculosis, addressing the rising number of cases of Silicosis would be important to keep a control on the number of cases of TB (Rupani 2023).

A study by National Institute of Occupational Health, Ahmedabad, finds that 'Pulmonary Tuberculosis when associated with Silicosis

has 2.5 times failure of treatment outcome in comparison to simple Pulmonary Tuberculosis' and this dual health hazard makes it impossible for workers and their families to survive, leading to a vicious web of death, widowhood, child labour, persistent malnourishment and intergenerational bonded labour.

### 3. Systemic Problems at National Level

#### Silico-Tuberculosis – A Fatal Comorbidity and Need for Systemic Actions

The deeper underlying factors leading to high incidence of Silicosis in tribal communities are related to the very processes of economics and business models of development and resource exploitation that have serious negative impacts on their health and social security. The increasing demand for infrastructure growth, urbanisation, fast track economies competing globally for business models of development indicators have all been leading to more large scale resource exploitation, export and consumption of minerals and metals. Forced displacement and seasonal migration have become a normalisation of exploitative development economics for most tribal groups in India today, that has led to the prevalence of both TB and Silicosis in majority of tribal-dominated districts in Odisha, Jharkhand, Chattisgarh, Gujarat, Rajasthan, Maharashtra, Telangana and increasingly now, in Andhra Pradesh as well. Estimates of tribal population affected by Silicosis are absent except for scattered sites that have been consistently monitored by local groups (CSE, July 2016). In states like Rajasthan, Jharkhand and Madhya Pradesh, strong local movements have been representing cases of affected workers for relief and rehabilitation. In M.P, in the districts

of Betul, Jhabua, Alirajpur, Panna and others, Jan Swasthya Abhiyan and other health rights groups have been convening people's health assemblies and raising the concerns of Silicosis affected workers particularly in tribal communities. A few such reports map the critical groups and areas that are affected like the Sahariyas who are a PVTG group having dominant prevalence of both TB and Silicosis in Madhya Pradesh and Chattisgarh with estimates ranging from 1270 to 3294 per 100000 population (Rao VG et al, 2021). This is more than ten times compared to the national estimated prevalence of 320 per 100000 population. However, lack of political will and the power dynamics prevent accurate identification, rehabilitation or prevention among workers and punitive actions against exploitative contractors and mine owners. ST groups like the Gonds, Bhils, Bhilala, Bhariya and others are also reported to be seriously affected or at risk of both TB and Silicosis although comprehensive health assessment is absent with regard to Silicosis. For instance, the AIGGPA report on Madhya Pradesh tribal health plan did not even mention Silicosis as one of the health problems of tribals in its road map, although pockets of scheduled and non-scheduled areas are

seriously affected by the dual fatality of Tuberculosis and Silicosis. The report, however, mentions the recurrence of Tuberculosis, without going into the complex causative interlinkages between the two.

Due to the lack of a comprehensive policy and programme for prevention, control, and rehabilitation, NGOs and other non-profit organisations have filed Public Interest Litigations (PILs) in the Honourable Supreme Court and High Courts to bring justice to the plight of those who have the disease. The National Human Rights Commission (NHRC) in its report on Silicosis, which was submitted to the Parliament in 2010, called attention to the suffering of Silicosis victims and recommended strategies for the disease's prevention, control, and alleviation for those who are affected by it. It also identified Gujarat, Jharkhand, Karnataka, Madhya Pradesh, Rajasthan and West Bengal as endemic states for Silicosis. Despite persistent research studies, media reports and NHRC interventions, the crisis not only continues but may likely be growing in figures beyond what is officially acknowledged (Baviskar, 2008, EPW). Some estimates of informal and artisanal mine workers were given by researchers in the past where more than 12 million informal labour in this sector was reported, a far larger number in comparison to what the DGMS data would admit (Lahiri-Dutt, 2001). According to the Directorate General Factory Advice Service and Labour Institute (DG-FASLI) and the Directorate General of Mines

Safety (DGMS), a total of 250,000 workers are exposed to Silicosis till now.

Rupani (2023) notes that over 92% of workers are working in informal employment, which means they do not have access to social security benefits. There is no provision for health insurance, provident fund, or leave with pay for these workers. This and the lack of surveillance data on Silicosis complicate the diagnosis and treatment of Silicosis among the people who, due to the environment they work and live in, run high risks of contracting such ailments (Silicosis, pulmonary tuberculosis, chronic bronchitis, emphysema, lung cancer, mycobacterial, fungal, and bacterial lung infections).

As far as interventions are concerned, labour unions and groups working on behalf of Silicosis victims have, time and again, sought legal recourse that led to partial relief. However, laying down the onus of responsibility across the spectrum of contractors, employers, state and inter-state authorities and business groups over accountability have largely remained unaddressed at a policy and implementation level. Rather, labour, mineral and environment laws are consistently being diluted, leaving the responsibility of prevention and rehabilitation in stagnation. By laying emphasis on proof of employment in a mine on the workers, state institutions have, time and again, used it as a pretext to deny rehabilitation or compensation to victims despite the knowledge that the majority of mine workers are from informally/

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*I worked in stone mines only for a year or so. Recently in the past year, I started experiencing breathing problems, constant coughing, and chest pain. Then I went to Panna to get myself checked. I was told that I have both silicosis and TB.*

*- Mulayam Singh, Madaiyan*



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illegally operating sites, with workers having no registered employment or identity given by mine owners. Even where the disease is visible, insisting on documentary evidence of the workplace has been an escape route for concerned authorities, to elude rehabilitation and prevention. As per the CAG Revenue report of Madhya Pradesh of 2018, illegal mining is rampant with regulation being poor, whether with respect to mineral dues, workers or environmental destruction. *“The illegal mining activities were not being detected in time and prevented, causing damage to the environment and livelihood of nearby inhabitants, as well as loss of royalty to the Government.”*

The same report *“shows an increasing trend in illegal mining cases of minor minerals”* and that *“Mining Surveillance System has failed to detect the actual illegal mining cases registered by the DMOs or there were flaws in the inspections at the local level”*.

A major fall out of these findings also conclude that large numbers of mine workers are missing from labour records if the mines themselves are unreported and hence, the scale of Silicosis affected could be much larger in real numbers. The CAG’s findings that large revenue losses due to poor regulation of mines and poor collection of revenues and DMF funds also indicate a huge loss not only

in the form of royalties, but also of funds that could have been available for the health and welfare of workers. On the other hand, the Ministry of Labour and the DGMS, whose primary responsibility it is, to ensure the Mines Act be implemented along with mine safety regulations for workers, as shown above, is confronted with non-performance issues as reported by the CAG. This is the case across other states having small and large mines.

The Constitution of India enshrines detailed provisions for the rights of the citizens and other persons and for the principles in the governance of the country labeled as “Directive Principles of State Policy”. These Directive Principles provide for securing the health and strength of employees, men and women, that the tender age of children are not abused, that citizens are not forced by economic necessity to enter avocations unsuited to their age or strength (Article 39), just and humane conditions of work and maternity relief are provided (Article 42), that the Government shall take steps, by suitable legislation or in any other way, to secure the participation of employees in the management of undertakings, establishments or other organizations engaged in any industry (Article 43A), for ensuring that no child below the age of 14 is employed to work in any factory or mine or engaged in any other hazardous employment (Article 24).

**Table 1: Shortfall in inspections by mining inspectors**

Year	Total number of mines in test-checked units	Total inspections to be conducted as per norms	Number of inspection done as per information furnished to audit	Number of Inspection Reports available	Short fall in number of inspections
2015-16	736	1,472	185	6	1,287
2016-17	736	1,472	146	3	1,326
2017-18	736	1,472	150	11	1,322
<b>Total</b>		<b>4,416</b>	<b>481</b>	<b>20</b>	<b>3,935</b>

**Source: CAG Revenue report of Madhya Pradesh (2018)**



***However, even though child labour below the age of 10 has considerably reduced in most small scale mines, we increasingly find children between the ages of 13 and 18, who continue to be the most vulnerable age group facing several hardships, and succumbing to the two diseases within a period of ten years, by which time they are still in the age group of 25-35 years.***



This continues to pose an alarming situation when such a young age group is vulnerable to disease and death, reflected in the large number of young widows found in many Silicosis affected villages. The labour laws allow for apprenticeship from the age of 16 which go against the definition of the child of most other laws, providing an escape route for non-accountability towards children exposed to very hazardous work.

Some states have relented to people's actions and drafted Silicosis prevention and rehabilitation policies like in the states of Rajasthan, Haryana and West Bengal. A brief comparison between state policies is as follows with regard to welfare schemes for workers of Silicosis and Pneumoconiosis:

**Table 2: Welfare schemes for silicosis affected in three states**

Sr.	Name of Welfare Scheme	Haryana	Rajasthan	West Bengal
(i)	Rehabilitation Assistance	Rs. 5,00,000/-	Rs 3,00,000	Rs. 2,00,000
(ii)	Assistance on death	Rs. 1,00,000/-	Rs 2,00,000	
	Assistance on Death before getting Rehabilitation Assistance			Rs. 4,00,000
	Assistance on Death after getting Rehabilitation Assistance			Rs. 2,00,000
(iii)	Funeral Assistance	Rs. 15,000/-	Rs. 10,000	Rs. 2,000
(iv)	Silicosis Rehabilitation Pension	Rs. 4,000/- per month	Pension equivalent to persons with disability, would be sanctioned irrespective of income criteria.	Rs. 4,000

Sr.	Name of Welfare Scheme	Haryana	Rajasthan	West Bengal
(v)	Family Pension	Rs. 3,500/- per month	Widow pension to wife, and/or benefits under Palanhar would be provided irrespective of income criteria.	Rs. 3,500
(vi)	Financial Assistance for Education	Rs. 5,000/- to Rs. 12,000/-		
	Class 1-5	Rs. 5,000/-		
	Class 6-8	Rs. 6,000/-		
	Class 9-10	Rs. 8,000/-		
	Class 11-12	Rs. 10,000/-		
	ITI diploma / graduation / post- graduation	Rs. 12,000/-		
	XI			Rs. 4,000
	XII			Rs. 5,000
	BA/BSC/BCOM			Rs. 6,000
	MA/MSC/MCOM			Rs. 10,000
	Medical/Engineering			Rs. 30,000
	Training under IITS			Rs. 6,000
	Polytechnics			Rs. 10,000
(vii)	Kanyadaan Assistance on the occasion of marriage of daughter	Rs. 51,000/- Up to three daughters		Rs. 25,000
	Education and Skill Development Assistance to Daughter			Rs. 25,000
(viii)	Financial Assistance on Marriage of Sons	Rs. 11,000/- Up to two Sons		
(ix)	Legal Assistance		State government to provide legal assistance to pneumococcosis patients	
(x)	Family Welfare Assistance		Patients and families to receive welfare schemes at par with ASTHA card holders	





*Workers at a diamond mine in Panna district*

There are several challenges to accessing the entitlements offered in each of the state policies while some of the states like Madhya Pradesh which has a high prevalence of both TB and Silicosis have not even formulated their Silicosis prevention and rehabilitation policy, leaving behind large numbers of affected workers and their families in deep financial crisis and physical suffering. In India, 80% of health care is provided by the private sector, but in rural parts, health care is provided by unqualified medical practitioners who do not have knowledge of occupational health. Hence people prefer to go to private hospitals which puts them in financial debt. In almost all the states, as reported by Occupational Health and Safety Association, Jharkhand, the Silicosis affected are working or have worked as informal labour with very poor regulation by authorities across different categories of hazardous industries and shifting the blame between different actors has left thousands of workers suffering without relief either on improving work safety standards or in rehabilitating affected workers and their families. In Rajasthan where monetary relief is provided to workers, the onus is on workers to get a diagnosis and prove their occupational history, which is challenging in an unregulated industry like

mining in India.

In reply to a recent complaint filed on behalf of victims, with the list of Silicosis and Tuberculosis mine workers who were diagnosed as positive by the local PHC in Panna, the Directorate General of Mine Safety, merely enquired “whether the person who died due to suspected Silicosis was working in a legally operating mine, and if so, the address of the mine and the owner”. Such queries do not give confidence that occupational health of workers is taken seriously, where the onus of providing evidence of employment in order to avail of state relief measures, still falls on the workers despite several judicial directives in support of the victims. It also indicates the lack of regulatory intent in identifying illegally operating mines even when the numbers of Silicosis affected are found mostly in the informal sector. It demonstrates more an intent to evade relief and welfare to dying workers and their families, while being complicit with the illegal extraction and trade.

The disconnect between mining induced environmental and social problems and the due diligence of other ministries and departments reflects huge gaps in both policy and administrative aspects. Particularly for tribal

communities living outside the Scheduled Areas, they get poor or no attention from the Tribal Welfare schemes and administration as was seen in the case of the study areas in Madhya Pradesh on the lack of linkage to Ashwasan programme and other tribal welfare schemes. The other glaring opacity in both information sharing and implementation is the District Mineral Funds (DMF) in many states. The absence of proper assessment of mining affected communities and their needs and the disconnect between the PMKKKY expenditures under the DMF legal entity, with the ground level losses and rehabilitation demands of mining affected communities is visible in many states, more so in Madhya Pradesh. The PMKKKY guidelines clearly specify the utilisation of these funds to directly and indirectly affected mining communities, with women and children falling under high priority segment.

The guidelines specifically direct the funds to be utilised for:

“Health care – the focus must be on creation of primary / secondary health care facilities in the affected areas. The emphasis should not be only on the creation of the health care infrastructure, but also on provision of necessary staffing, equipment and supplies required for making such facilities effective. To that extent, the effort should be to supplement and work in convergence with the existing health care infrastructure of the local bodies, state and Central government. The expertise available with the National Institute of Miners’ Health may also be drawn upon to design special infrastructure needed to take care of mining related illnesses and diseases. Group Insurance Scheme for health care may be implemented for mining affected persons.” Despite the DMF committees and rules being set up in most states, the linkage to occupational health concerns of workers and health and livelihoods of mining affected to repair the damages caused by mining operations are not only absent, but there are huge lapses in collection of funds

from defaulting companies and contractors and equally high non-compliance and misutilisation of funds where they have been collected. Further, large scale illegal and unregulated mines are reported where both royalties and DMF collections are absent.

The CAG Compliance Report of 2021 for Madhya Pradesh, Chapter III, is a case in example, for such starkly visible non-compliance and poor performance, despite the 51 districts that have the DMF offices, having acute problems faced by mine workers as well as local communities surrounding the mines.

- *“Non-compliance of administrative provisions relating to regular conduct of meetings of Board and Executive Committees, non-maintenance of basic records like list of the mining affected area and affected people and register of DMF fund payable and paid, irregular audit of accounts of DMF by the Chartered Accountants, non-disclosure of DMF activities in the website etc.*
- *Irregularities in the fund management of DMFs as to less contribution to DMF fund by the lessees, non-recovery of interest on delayed payment, funds lying idle in the DMFs, incurring disproportionate expenditure on eligible activities, Non-recovery of unutilised advance amount from work executing agencies etc.*
- *Irregularities in the execution of work from DMF fund such as short deduction of royalty, delay in completion of work, extra cost due to incorrect adoption of rate, improper survey, excess payment made to contractors/vendors etc. These instances of shortcomings, in aggregate, involved an overall impact of ₹ 206.21 crore”.*

The CAG report, after pointing to several irregularities related to non-identification of mining affected people and areas, non payments, non expenditures and diversion of funds, concluded that:

*“The fact remains that funds are lying idle in the DMF and the people of mining affected areas remained deprived of prospective benefits of the PMKKKY”.*

Public health and occupational health which are under the 60% high priority eligibility for expenditures under the DMF could have

been directly addressed from these funds for the welfare and rehabilitation of TB and Silicosis affected mining communities, the state health infrastructure, human resources and social security of communities - all remain neglected in the DMF institutionalisation framework and the linkages with interdepartmental schemes and needs.

## The Public Health System

The Public Health System in tribal areas is grossly insufficient in resource allocation - human, infrastructural, diagnostic and treatment facilities. Lack of accommodation, poor infrastructure, large-scale absenteeism and vacancies, poorly trained and unmotivated human resources and poor allocation of financial resources particularly in these remote tribal areas, are some of the reasons identified for the near absence of health care services.



***Patients with both Silicosis and TB are often not given the combined diagnosis of silico-tuberculosis, with accurate diagnosis largely being neglected due to a lack of priority by public health authorities on Silicosis, and absence of budgets, health infrastructure, personnel, surveillance and access to healthcare for the poor from affected communities.***



effective health care play a pivotal role in increasing Tuberculosis (TB) transmission within the community with high levels of poverty and a weak public health system, posing serious challenges in achieving effective TB control (Mistry et al 2017).

Many studies and reports reveal that tribal development strategies need to be more human-centred with health at its centre. The conventional, bureaucratised approach of looking at health issues for tribals in a sectoral, compartmentalised manner can have little impact on achieving health goals. Strategies to reduce morbidities and mortality among tribals would need to contain specific directions for establishing interconnectivity between resource ownership, income, food security, female literacy and good health. While the tribal population as such is extremely vulnerable to tuberculosis, some groups like women, children and elderly people tend to run a higher risk of tuberculosis infection and face a greater burden of the disease. This may be due to various factors like age, sex, political agendas and traditional patriarchal norms.

Loss of livelihoods and entitlements to land, agriculture, forest resources and food security have led to large sections of these groups shifting from cultivation and forestry, into daily wage and informal labour in hazardous industries. Further, lack of due diligence in

Patients with silico-tuberculosis have a higher risk of relapse and more treatment interruptions. A study found that a frequent cause of death in people with Silicosis is silico-tuberculosis or lung cancer. It is also difficult to treat them since Silicosis does not have any dedicated medical regimen, with most drugs used on patients for TB being rendered useless.

Secondary research findings state the need for a dual mechanism in terms of a method of eradication that encompasses both the social dimensions and the bio-medical aspect without which eradication of TB among the tribal population of India cannot be fulfilled by 2025. TB elimination strategy in India needs a pro-poor model of patient-centred care inclusive of nutritional, psycho-social and financial support, universal health coverage and social protection; and convergence with multi-sectoral efforts to address poverty, under-nutrition, unsafe housing and indoor pollution (Bhargava, Bhargava and Juneja 2021). All tuberculosis (TB) control programs in India since their inception have heavily depended on a medical model of diagnosis and cure. The socio-economic factors associated with TB control in India have not been adequately investigated. In spite of

the heavy investments made on TB control, its prevalence rates remain high among a few sub-populations such as the Scheduled Tribes who live in isolation far away from urban areas (Sharma and Pallai 2011).

The Social Action Plan including Tribal Action Plan is incorporated into the National Strategic Plan (NSP) with appropriate strategies stated to ensure universal access to quality TB services for vulnerable population groups. However, its implementation becomes challenging especially in tribal areas as different tribal groups have different contexts of vulnerabilities and lack of access to health services and concerned authorities to get their grievances addressed. These issues are therefore required to be addressed holistically involving all the stakeholders. TB screening which is an essential step towards eradicating TB among the tribal communities in India needs to adopt more proactive screening and diagnosis strategies. Given this context, Vyas et al 2017 suggested the need for community-based active case-finding to help identify more people with TB in tribal and remote rural areas by addressing barriers to health seeking as well as helping to reach the ambitious country and global notification targets. A study also found that delays in accessing



***My husband (Uttam Singh) and I returned home from work in the stone mine one day, when he developed a high fever along with chest pain and cough. His condition was bad, we tried calling the ambulance but to no avail. There was no auto in the village at the time, nor did we have enough money. Finally after a lot of calling, the ambulance came and we took my husband to the PHC in Panna.***

***- Tukkan Bai, Madaiyan***



the delivery of institutional obligations has led to mass seasonal migration through intergenerational cycles of hazardous mine labour and has seriously affected the health and well-being of Adivasi communities. The volatile situation of workers and tribals living and working in these areas reflects not only a major hindrance to the eradication of TB by 2050 as is the state's mission but also to the core principles of Sustainable Development. Secondary research suggests not only the need to revise the current policy for TB eradication and prevention in India but also highlights the need for a holistic policy on occupational health risks associated with working in hazardous environments like mines. Thus public health interventions in isolation without considering the above socio-political causes of ill-health, cannot provide long term relief and eradication of disease.

The public health system in itself is lacking on several fronts, leading to both poor performance and confidence deficit on the ground. Lack of accommodation, poor infrastructure, large-scale absenteeism and vacancies, poorly trained and unmotivated manpower, are some reasons on the ground for the near absence of health care services. The 'Peoples' Perception of Health Services', discussions with tribal communities in over a dozen villages brought forth some important insights regarding their perceptions of the existing health care system in the public sector: that the system is virtually non-functioning, even when endowed with all inputs; the treatment in the PHCs is unsympathetic and casual, if not hostile and exploitative; there is a serious crisis of credibility as, irrespective of the illness or complaint, the same medicines are administered - two white and one red - because of which most confessed to throwing them away; inconvenient timings and uncertainty - after a 10 km walk, which is the case with most villages, they normally find the PHC "closed", necessitating additional costs for the overnight stay, compounded further with high transaction costs - extortion by staff, "check-up" by a worker or the

pharmacist on account of the absence of the doctor; non-availability of inpatient facilities, forcing them to make their own arrangements for stay at the houses of relatives, the local headman, etc. Unable to afford to be sick for long, the tribals find it less expensive to seek private care, which has a measure of certainty, prompt services and accessibility. Or worse still, on account of the late release of budgets and sporadic supply, drug resistance is on the increase. These are realities that need to be captured for reducing morbidity and mortality levels (Jana, Rajak 2006).

In the tribal areas of many states the public health system faces huge gaps in human resources at the PHC and sub PHC levels and the last mile linkages at the community level. Even existing personnel have little in terms of incentives and remuneration for the persisting work required in identifying, motivating and follow up treatment for patients to successfully come out of their disease, atleast so far as TB is concerned. They are low paid and irregular, thus disincentivizing ground level health personnel in taking proper responsibilities or ensuring proper coverage of affected families. Particularly, given the challenges that poor tribal families face in their struggle to overcome hunger and unemployment, the constant migration, absence from native village and inability to miss even a day's work apart from other socio-economic hurdles prove difficult for adhering to treatment protocols.

For the ASHA workers on the ground, these factors of 'non-cooperation' from patients and lack of incentives to persevere with the patients, limit the scope of effective community outreach. The low honorarium ASHA workers in Madhya Pradesh receive (Rs.2000 and some meagre incentives for certain central schemes) even during the Covid pandemic and their requirement to be available at all times for community linkages, works as a low motivational factor for them to support TB and Silicosis patients (Gaon Connection 2021). Therefore, sputum collection, PHC re-

ferrals and other support are barely provided by ASHA workers. With Silicosis not even in the public health mandate, ground level personnel have received no orientation for case reporting or referral support.

An example is the state of health infrastructure in Madhya Pradesh's tribal pockets where shortages in medical and para-medical staff are glaring, as per the AIGGPA's assessment:

**Table 3: Human resource situation in community health centres in tribal and rural areas of Madhya Pradesh (as on 31st March 2019)**

Sl no.	Post	Required	Sanctioned	In Position	Vacant	Shortfall
<b>Tribal areas</b>						
1	Specialist	396	735	42	693 (94)	354 (89)
2	OB GYN	99	105	17	88 (84)	82 (83)
3	Paediatrician	99	420	3	417 (99)	96 (97)
4	GDMO	198	230	194	36 (16)	4 (2)
5	Physician	99	105	10	95 (90)	89 (90)
6	Ayush Doctors	99	57	33	24 (42)	66 (67)
7	Staff Nurse	693	707	636	71 (10)	57 (8)
8	Lab Tech	99	101	181	*	*
9	Pharmacists	99	137	122	15 (11)	*
10	Radiographer	99	87	61	26 (30)	38 (38)

Note: Figures in parenthesis are in percentage

**Table 4: Human resource situation in primary health centres in tribal and rural areas of Madhya Pradesh (as on 31st March 2019)**

S.no.	Post	Required	Sanctioned	In Position	Vacant	Shortfall
<b>Tribal Areas</b>						
1	Doctors	338	364	289	75 (21)	49 (14)
2	Ayush	338	290	63	227 (78)	-
3	Star Nurse	338	332	165	167 (50)	173 (51)
4	Pharmacists	338	332	243	89 (27)	95 (28)
5	Lab Tech	338	332	101	231 (70)	237 (70)

S.no.	Post	Required	Sanctioned	In Position	Vacant	Shortfall
6	ANM	338	332	380	-	-
7	Health Assistant (F) LHV	338	521	76	445 (85)	262 (78)
8	Health Assistant (M)	338	332		332 (100)	338 (100)

Note: Figures in parenthesis are in percentage

The National Health Mission, in its programmes for communicable and non communicable diseases has an expert group on strategies for palliative care services and such other services like *Rogi Kalyan Yojana (RKY)* which however, do not explicitly or implicitly cover Silicosis. Yet, the NHM provides scope for several windows of engagement and decentralised institutionalisation through its stated vision of Communitisation for community based monitoring, Village health and sanitation committees and improving the quality of services at the PHC level. It also proposes to collaborate with civil society groups for last mile community linkages. **“Any organisation with demonstrated experience of monitoring Public services, organising public dialogues or public hearings should be given priority to participate in the Community Monitoring committees.”** (NHM). The Mission also proposed to set up a Charter of Patients’ Rights that was to be displayed prominently at the PHC and set up grievance redress mechanisms under

the RKY, with a help desk and complaints receiving services. The Charter includes Right to Access Health Care, right to information, right to informed consent being sought, right to respect and dignity, among other rights. One barely finds any of these facilities linked at the community level, and least of all, grievance redress desks.

Despite these tall claims at providing health care services, there are serious lapses in legal compliance, budgetary commitments and convergence of funds interdepartmentally. These have resulted in lack of providing fair entitlements and reparations to local communities suffering from severe forms of ill-health and poverty, despite not lacking in revenues generated or that could have been generated from the mining sector alone, which are a serious denial of directly affected communities’ health rights. The number of widows among the tribal communities in the mining affected villages of Madhya Pradesh, clearly contradict the policy and programme claims to demonstrate this cruel crisis.

## 4. A Gendered Perspective - Global and National Scenario

### i) Gendered Analysis of Tuberculosis Prevalence

Most studies concur that a higher proportion of the 27.4 lakh diagnosed with TB in India are men and the ratio is approximately 2:1

between men and women (Global TB Report 2018). India’s latest figures state that, of notified TB patients, 39% are female (India TB

Report 2023). Tribals face a number of health risks, including infant and maternal mortality, malnutrition, anaemia, and malaria. There are gaping disparities in health status between tribals and inhabitants of metropolitan areas. (Beena Thomas et al, 2015).

Another study found that the prevalence of TB was three times higher in males as compared to females, possibly because males are more exposed to sources of infection like dust and air pollution. It is estimated that Tuberculosis affects an estimated 10 million people globally every year, of which around 3.2 million are women.

A study found that higher prevalence of pulmonary TB among elderly tribal people (over 65 years old) was attributed to latent infection, use of immunosuppressive medicines, and co-morbidities, with women being more vulnerable to the burden of this disease.

The National TB report of India, 2023 states that, “Gendered vulnerabilities for women

range from a perceived need to hide symptoms or possible illness due to stigma, prioritising household and caretaking responsibilities, constrained decision making power, lack of mobility, and limited autonomy over financial resources”. The lower diagnosis of cases among women could also be due to the reporting of fewer cases of TB among women due to various other reasons including poor access to healthcare services, poor diagnosis and poor reporting of cases among women (Uplekar et al., 2001). It may also be due to physiological reasons. There is evidence to show that the presentation of pulmonary TB among women may be somewhat different from men, contributing to delays and making it difficult to diagnose TB in women. While men generally present symptoms of fever, haemoptysis and night sweats, women could present common symptoms or non-specific findings such as fever, body ache, loss of appetite and fatigue (Long et al., 2002). The same study indicates that more men report microbiologically confirmed pulmonary TB



*Men moving slabs of stone at a mine in Panna*



and women are more likely to have clinically diagnosed pulmonary TB and extra-pulmonary forms of TB (Balasubramanian et al., 2004).

Men are at greater risk of developing TB due to their employment in mining, quarrying, metals and construction industries where the work is heavily gendered. However, some industries in South Asia employ a high proportion of women, for example, up to 80% of workers in garment factories of Bangladesh (Zafar Ullah et al., 2012), more than 80% of beedi workers and up to 50% of workers in tea gardens of Assam are women (Talukdar, 2016), the latter two in India. In India, many of the tea estate workers are migrant labour from tribal communities. For example, in West Bengal most workers are from Santhal and other tribes from neighbouring Jharkhand and Odisha, working in very poor, undernourished and overcrowded conditions (Sarkar 2019). Workers often use solid fuels for cooking, besides lacking knowledge of the causation, transmission and prevention of TB (Chelleng et al., 2014). Hence the risk, although high, appears to be invisible in the case of women. In M.P, high prevalence of TB has been identified through different studies among the Sahariyas (Sheopur, Vidisha districts), Baigas (Dindori district), Bh-

arias (Chhindwara district), Gonds (Panna district), while in other districts they are not so widely reported, although the disease exists in alarming proportions and reported as not having been effective in bringing those infected out of the disease, despite the DOTS intervention (AIGGPA, 2011).

For women who work outside their houses, the fear of losing wages and the consequences of absence from work, hinder care-seeking. Traditionally, women are generally confined to household work, agriculture, and caregiving to children. The environment they live and work in can often become toxic, exposing them to tuberculosis and related diseases. As per traditional patriarchal norms, women are expected to look after the home and family and be responsible for all household work, including cooking, cleaning, caring for children, the elderly and the sick.

The perceived subordinate status of women reduces their access to resources, including money, nutritious food, mobility and decision-making powers over their own health. There is growing evidence that use of solid mass or biofuels for cooking coupled with poverty, lack of ventilation, small homes or multipurpose rooms and spending prolonged time in the kitchen are associated with an in-

“



***I am the eldest daughter-in-law, hence have more responsibility in my husband's house. Apart from cooking and other household chores, I also work in the fields and go for daily wage labour sometimes. I continue to work even when I do not feel well due to my TB condition. The only time I went to the hospital was when my mother came and took me there. But even my mother does not have enough money and struggles to take care of my nutrition when I am home.***

***- Surmila, Umraavan***



”

creased risk of TB (Kurmi et al., 2014). In case a family member falls sick the onus is often on the women of the family to look after the sick and cater to their needs. As the principal care providers for the sick, women are vulnerable to exposure to TB either before or after the diagnosis of TB within the family.

Women may be constrained from protecting themselves from the illness if they do not feel empowered enough to ask those with TB to practice cough hygiene or wear a mask or appropriately dispose of sputum. They fear maintaining a distance from their intimate partners, whether they are caregivers or patients, and often face domestic violence if they try to maintain distance or avoid sexual activities. This, coupled with the fear of being diagnosed with TB and poor attention within the family to women's health in general, may result in delayed attention to the symptoms and a late diagnosis.

The TB report of 2023, particularly brings to attention the vulnerability of pregnant women in India, as women "particularly in the reproductive age group (15-49 years), during

which many changes happen in a woman's body, may experience the disease differently. Moreover, diagnosing TB disease in pregnant women becomes challenging due to common non-specific symptoms in both TB and Pregnancy." All of this can increase a woman's risk of contracting TB infection and the risk of pregnancy while they are still not cured from the disease. Tuberculosis infection in pregnant women can often be life-threatening and cause harm to both the mother and the child. There is enough evidence that pregnant women and women in the postpartum period face a higher risk of TB, one of the leading non-obstetric causes of maternal mortality in low-income countries like India. (Bates et al., 2015) These researchers underline that immunological changes during pregnancy make new infections as well as activation of latent infection more common among this group. The presence of TB disease during pregnancy, delivery, and postpartum is known to result in unfavourable outcomes for both mothers and their infants. These outcomes include a roughly two-fold increased risk of preterm birth, low birth weight, intrauterine growth restriction, and a six-fold increase in



*A woman making rotis (flat bread) on a firewood stove in Panna*

perinatal death (Gendered perspective on Tb report 2022). Physiological changes in pregnancy have an impact on the epidemiology of TB (Mathad and Gupta, 2012). Women who are living with HIV face an even greater risk of getting TB in the postpartum period (Gupta et al 2007).

Studies note that considerable stigma found among people affected by TB was rooted in misconceptions related to the disease — of it being dangerously contagious, transmitted via sex and incurable. This stigma affected women more than men, feeding into the narrative of immoral women succumbing to the infection and causing substantial psychological trauma. The socio-economic and psychosocial impact of TB ranges from high costs of diagnosis and treatment, expenditure on unnecessary tests and supplements, disruption in work and schooling, and stigma, harassment and rejection faced by those affected by TB. Though studies of catastrophic expenses on TB pertain to both men and

women, most studies underline that the costs incurred by women were more than by men (Ananthakrishnan et al., 2012).

It also has to be understood that women might find it more difficult to travel the distance to a public health centre for seeking care. This could be due to reasons like social stigma, lack of time, public transport and resources for hospital visits and self-care. A gender-responsive health programme that acknowledges different norms and roles for women, men and transgender persons; takes account of gender-specific needs; addresses the causes of gender-based health inequity; identifies ways to transform harmful gender norms, roles and relations; promotes gender equality; and includes strategies to foster equal power relationships between women, men and transgender persons -these have been stated as urgently needed by the WHO. (Gender mainstreaming for Health Managers, 2011).

## ii) A Gendered Analysis of Silicosis Prevalence

As with Tuberculosis, most Silicosis patients are reported to be males, although women are also working in the mines and quarries, and do contract the disease. A major phenomenon of this disease is the high rate of death among the Silicosis affected, where most women end up as widows, if not patients themselves, and are left with a lifelong burden of single-handedly raising their children and repaying the debts incurred for the health expenses of their husbands, sons, fathers and other family members. Many widows and single women end up as mine workers and become most vulnerable to Silicosis in a very short period.

Men often face a higher risk of Silicosis due to the nature of the work they are allotted.

Rajavel et al (2020) through their study in sand mines of Haryana found the mean age of entry into mines for the male worker was ( $19.54 \pm 5.82$ ) significantly lower than for female workers ( $22.23 \pm 6.69$ ). This higher mean age of entry into mine for females is due to the reason that females start working in mines only after marriage or when their husbands get diseased or die due to Silicosis. The study also shows that the majority (94.5%) of male workers were engaged in stone cutting, drilling or both, while most of the female workers (93.4%) were involved in loading stones, cleaning stone waste or both. While several studies by Han et al 2014, Govinda Gowda et al 2022 and Rajavel et al 2020 have indicated a lower rate of contracting the disease among women. Anxiety and de-

pression related to almost 90% of Silicosis patients in a study in China also indicated that females had lower chances of having social security which inevitably affects their mental health. Another study highlights that females with Silicosis were more likely

to die with broncho-pulmonary conditions, vs. the males of the same group (Morozova 2012). However, the survival rate among the females over the studied period was higher than that among the males (ibid).

**Table 5 – Gender and levels of exposure to silica dust (Rajavel et al 2020)**

Work Classifications	Type of work	Males (%)	Females (%)	Total (%)
High dust producing work	Stone cutting	26 (20.3)	3 (6.5)	29 (16.7)
	Stone drilling	25 (19.5)	0 (0)	25 (14.4)
	Stone cutting and drilling	70 (54.7)	0 (0)	70 (40.2)
Low dust producing work	Driver in mines	1 (0.8)	0 (0)	1 (0.6)
	Loading stones	1 (0.8)	11 (23.9)	12 (6.9)
	Cleaning stone waste	2 (1.6)	22 (47.8)	24 (13.8)
	Loading and cleaning stone waste	1 (0.8)	10 (21.7)	11 (6.3)
	Mine inspector	2 (1.6)	0 (0)	2 (1.1)
<b>Total</b>		<b>128</b>	<b>46</b>	<b>174</b>



*A woman worker at a diamond mine in Panna*

Similar to trends seen in TB cases most of the informal workers tend to be women because they are not officially employed as mine workers. This puts them at a greater risk of contracting the infection by not getting adequate treatment and the additional social burden due to patriarchal norms. This often causes women workers not to come forward to get diagnosed or treated. The major burden of Silicosis on women comes from the fact that they are the primary caregivers in most cases and often have to neglect their own well-being to care for the ill and provide for the family. Reports by Mongabay show that in Rajasthan, stone mining is the main cause of Silicosis. Widows whose husbands have died of Silicosis are then forced to go back to the same mines in order to survive and end up contracting Silicosis or other diseases as well. In many cases, the women end up in a vicious cycle of loans or mortgaging their jewellery, for treatment of ailments or

simply to survive. While mining policies and other development policies talk about sustainable and just transitions, the only transition they (women from mining-affected families) have witnessed in their lives is the successive deaths of their husbands, sons, brothers and other family members, from mining-associated diseases.

There have been some studies that brought a focus to the gendered dimensions of mining and of the occupational health problems of mine workers. Many report that women informal and artisanal mine workers are not enumerated, often unpaid, and not recognised as falling in the mine worker category (Lahiri-Dutt 2001). However, they argue that women's work whether in licensed or unlicensed mines is heterogeneous as they perform multiple jobs usually where mechanisation is low and the work is labour intensive (Lahiri-Dutt 2001). Therefore, they are



*A woman worker at a stone mine in Panna*

more prone to exploitation, whether of wages, type of work, access to safety equipment or safe work environment, whether environmentally or socially. As patriarchal norms exist in all sectors, women in the mining sector are all the more vulnerable to abuse, given the male dominated nature of the industry. “In India, women’s lack of ownership of the small mines and quarries reflect their low control and rights over natural resources, especially land” (Agarwal, 1994). Comorbidities for women suffering from Silicosis could be fatal, particularly for pregnant women. As reported in a case study of pregnancy in a female Silicosis victim, “though pregnancy does not appear to affect the course of silicosis, there is still a risk of acute progression of the disease due to alteration in immunity, causing fetal complication and maternal morbidity”.

Therefore the many ways in which women are at risk of contracting this disease or of having to face the consequences of male members suffering and succumbing, continues to be treated unsympathetically, at least by the instruments responsible for rehabilitation and prevention. “Women being responsible for the subsistence of families, often bring chil-

dren to work to assist the mothers, exposing them to the harsh working conditions at an early age. Whereas more attention is on reducing child labour in the quarries, improving the status and the working conditions of the mothers is yet to find a place in the development agenda. (Lahiri-Dutt 2001).

As primary and secondary victims of Silicosis, women’s rehabilitation whether as workers or as widowed households burdened with debt, poverty and ill health, is critical to the immediate and long term sustainability of entire communities of Silicosis affected. Women’s rehabilitation is primary to prevention of child labour, migration, chronic malnutrition and reversing the social, educational, economic and emotional bondage these communities intergenerationally face. Hence, strategies for Silico tuberculosis interventions cannot be only social and biomedical but also require political, legal and ecological dimensions of understanding and approach.

The stories that we present in the next section are firsthand narratives of women’s ground realities, which stand as examples of all the above analysis and findings.



*A woman worker at a stone mine in Panna*

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## **Section II**

# **Stories from the Ground: Caregivers of Panna**



## 1. Introduction and Field Study Methodology

This section attempts to bring the voices of women as patients, widows and caregivers of family members having Silicosis and Tuberculosis. These are first hand narratives of their struggles dealing with the medical, social, psychological and economic burdens at the domestic and the public levels. In places like Panna, where the study was conducted, the customary tribal social practices have been overpowered for long, by dominant non-tribal customs and patriarchal behaviours like wearing of purdah, women not being allowed to speak in the public domain, alcoholism and domestic violence compounded by the harsh conditions of land alienation to non-tribal groups and to development and conservation projects that increased their dependency on mine labour. While individual land ownership has shrunk due to multiple forms of dispossession for mining, tiger reserve and non-tribal land grabs, the collective livelihood and decision-making spaces of the forest for women, became very restricted, thereby denying women access, ownership and security from these natural resources.

Accompanying their husbands to mine sites or other forms of labour, or migrating alone as widows and single women, has brought further vulnerabilities. Women as informal labour and migrant workers, have no social agency outside of their villages and struggle in highly fractured social structures within their villages and in relocation sites which are located on the peripheries of dominant non-tribal populations.

Further, the context in which they survive is a complex socio-political dynamics of conservation, extractivism, tourism and other commercial growth models which do not take into account women's own growth, traditional knowledge practices, customary wisdom and ecological capabilities. They have to survive with multi-dimensional challenges of not having enough agricultural land, unable to forage in the forest both due to restrictions and the fear of tiger attacks, negotiating with mine owners, non tribals, forest guards, tourists, traders, local liquor cartels, unresponsive medical and administrative



*Our team assisting patients at the government health centre*





*A barefoot health volunteer on a routine follow-up visit to check on a TB patient's progress*

structures and police, to list a few of the exploitative chains they confront on a daily basis. Their realities need to be addressed, therefore, from multiple new dimensions of the medical, legal, economic, environmental and social systems that need reconfiguration in order to bring justice and well-being to women and their children. Today these ground challenges have far reaching linkages to the global climate politics of net zero, afforestation, biodiversity conservation, extraction and nature based solutions (NbS).

This study was conducted in 12 villages. The study used multiple methodologies at the ground level. As part of our field activities, we collected household level socio-economic and resource utilisation data. Health assessment was conducted by our Barefoot Health Volunteers (BHV) through household surveys, information was gathered from patient records as part of our referral work with the Primary Health Centre (PHC) and health personnel. The Barefoot Health Volunteers

have worked on the ground to identify patients suspected of having either Tuberculosis or Silicosis or both, and have been providing referral support to them for diagnosis and treatment at the Panna PHC, community awareness and patient follow-up, in order to effectively assist the affected families. With the help of youth volunteers, NGO groups working on Tuberculosis and student interns, intensive participant interviews were conducted and FGDs were held in 6 villages (Madaiya, Kaimasan, Darera, Bador, Umrawan, Hirapur). We selected households from all these villages where at least one person has worked in the stone mines, using a cluster sampling approach. The total number of households interviewed for the Caregiver stories in Panna, were 38 families from 6 villages. We present here the findings from 12 villages and from some of the participants' individual stories in these 6 villages. The data on TB and Silicosis is based on families who came forward to get diagnosed and treated through our barefoot health intervention

programme and hence, may not be the total figures of these two illnesses. Further, many have already died, going by the number of widows present in each village and, descrip-

tions from the women indicate a high probability of death having occurred due to one or both of these conditions.

## 2. Panna - The Study Area

Panna district has a high concentration of mineral activities. It has India's largest diamond producing mine and has several stone quarries which have been historically in operation, both legally and illegally. Due to the irresponsible nature of stone mining, operations were banned in the recent past, but minor mineral operations continue and have been opened up again in many places. The first formal diamond mine licensed to the National Mineral Development Corporation started operating in 1967. Although the lease expired and there were legal concerns regarding its location in the core area of the

PTR, the NMDC managed to get an extension during the Covid time in 2021, after an investigation by a Supreme Court appointed committee laid out conditions for its operation. The mine is located in the core area of the Panna Tiger Reserve and a whole industry of small-scale diamond and stone mining operations boomed in this forest. The Gond Adivasis living here became victims of the mines as well as of the tiger reserve when entry into the forest and farming in their lands became prohibited. Most families ended up being more dependent on the informal mines, both diamond and stone quarries. The direct



*Tailings dam near the diamond mine in Panna*

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*I have both TB and silicosis. I can't go outside for work so I only depend upon some agriculture here in the village and some money which my sons send. Both my sons work as daily wagers in the furniture industry in Haryana. Due to their work, they can only afford to return during harvesting season to help us out in the fields.*

*- Mulayam Singh, Madaiyan*



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long term effect of working in these unregulated mines manifested in the form of Tuberculosis and Silicosis among many men and women in this region.

The case of large numbers of mine workers affected by Silicosis and Tuberculosis in Panna, has for long, been highlighted by local groups

and media. Hirapur, Janwar, Madla, Nayi Basti, Kaneri, Talgav, Pithmapur, Modaikhera, are relocated colonies who lost all their land to the PTR and were forced to resettle in/near non-tribal villages with neither land nor forest resources accessible to them. Umra- van, Kemashan, Bador, Darera are some of the villages where the Gonds had to give up



*A family migrating from Panna for work*

large areas of their farmlands and community forest lands to the PTR. Fifteen years after relocation, they are still struggling to find a source of livelihood, mostly by migrating for seasonal work. At the time of evictions, as gathered from the interviews and community narratives, many of the tribal families were already afflicted by both the diseases, and left untreated. Unmindful of their condition, they were made to relocate, some of them in peak winter, and forced to live under the trees and open air, with no food or livelihood. There are stories of how deaths became frequent soon after relocation, as ailing members could not cope with the starvation and lack of basic amenities. Many of these families were dependent on women's labour as male members were too ill to work. Women struggled to find daily wage labour and had to walk a long distance mostly to Panna town for construction work or for selling firewood. Unable to sustain locally, they were forced to travel to far off places as migrant

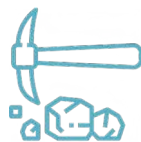
labour, having no other source of livelihood.

Access to the PHC or any medical facilities became even more difficult with no roads or public transport available in these relocation sites. With the burden of walking longer distances for work and the deteriorating health condition of their male members, women in these families experienced severe stress and ill-health. Caregivers become patients too, yet could not afford to consider themselves patients in need of care and support. Given these extreme conditions in which women have been pushed into, the spill-over stress has been on children, many of whom had to quit school and start working in the mines and resort to substances, imitating their elders, as a coping reflex to the hazardous labour conditions.

The stories we captured from the women in these villages carry the heavy-hearted and unredressed tales of hunger, despair, guilt and anxieties that they face each day.



***Women bear the double burden of caregiving and of guilt that they had to pull their children out of school and push them into the harsh mine or construction labour work, fully aware of the impending health problems to their young.***



### 3. Silicosis and Tuberculosis Affected Villages

This study was conducted in 12 villages of which in 6 villages we gathered detailed household-wise information of tribal families affected by the two diseases.

**Table 6 – TB and silicosis patients identified and diagnosed in the PHC in 2022-23**

SI No	Village	Panchayat	Diagnosed TB Patients*	Diagnosed Silicosis Patients	Widows **
1	Madaiyan	Bador	9	3	16
2	Umraavan	Bador	7	2	5
3	Hirapur	Jamunayi	9		19
4	Bador	Bador	10 males	2	32 males +2 Female deaths
5	Darera	Manor	5	-	18
6	Kaimasan	Bador	4	1	17

\*Diagnosed & Suspected deaths due to Tuberculosis/Silicosis

\*\* Widows who lost their husbands due to suspected TB/Silicosis

**In Hirapur**, all the 18 Gond families who relocated from Umraavan barely live in the relocation colony as it provides them no land for agriculture or even labour opportunities. The relocation site is surrounded by barren land and plantations of the forest department, for which they have no entry. Thus livelihood locally, is almost negligent. Seasonal migration is high as ST families find it difficult to get consistent local wages from the agriculture and construction labour work in Panna. Therefore, for most part of the year, they are going for sugarcane cutting, agriculture and construction labour in places like Delhi, Gwalior, Gurgaon, Chhattisgarh, Punjab, Bihar, Mysore, Surat, Haryana and surroundings of Mumbai. Many of them either do not have necessary entitlements to avail of MGNREGS or do not show interest in even applying for these due to low wages,

domination of non-tribals, inconsistent and insufficient days of work guarantee and inordinate delays in payment of wages. Many reported that they did not even receive the wages of pre-Covid period work.

The entire money they received as compensation under the World Bank financed resettlement programme was exhausted in purchasing a common piece of land for housing (for which, till date, they do not have proof of purchase or ownership), construction of houses and for clearing the debts incurred for health expenditures, apart from miscellaneous amounts for marriages and purchase of small assets. Of the 18 families, the majority of the households are suspected to have either Tuberculosis or Silicosis (confirmed/suspected) and many of them were forced to relocate in this condition of illness. Re-

cently, one woman aged 35 years has been confirmed with TB, after our team assisted her in approaching the PHC for testing. She is now undergoing treatment while her husband was already undergoing the DOTS course. Others are untreated or have developed MDR (multiple drug resistance). Out of 75 total Gond families in the village, 19 women have been widowed and 54 children are out of school as of January 2023.

**In Umravan**, 13 Gond families chose not to relocate despite losing all their land for the PTR and having most of the basic amenities like electricity, road and transport disconnected by the authorities in order to force people to relocate. Today some of those who had left the village have returned, not being able to survive in the relocation sites. As of January 2023, there are 13 families who survive through collection of Mahua, Chironji, Amla, daily wage labour in Panna town, collection of firewood and largely, seasonal migration. They were initially promised employment in the NMDC diamond mines but

none have been given jobs. There is a long history of working in the stone and diamond mines for the Gonds in Umravan (mostly reported as not knowing who the owners were and not having any worker registration cards). Among those who left and those who remained, a considerable number of men were afflicted with suspected Silicosis and Tuberculosis. A few were under the DOTS treatment process, yet had to leave abruptly and discontinue or erratically undergo their treatment, with little effect, as seen from the case histories of patients we profiled. Those who remained in the village refrained from utilising the compensation money until the time of Covid when they faced severe distress. Hounded by money lenders, hunger and Silico-Tuberculosis related health problems, resulted in the compensation money being spent on health emergencies and payment of debts to money lenders. Women, children and male members, all suffer from malnutrition and hunger, from the description of health problems shared by them. As of January 2023, identified and diagnosed



*A woman collecting Mahua in Panna*



*A widowed woman working in a wheat field in Madaiyan village*

TB patients are 5 in number and these could be suspected Silicosis as well. Repeated use of the DOTS course and failure of the same has driven the Adivasis into the hands of the private health practitioners and quacks, resulting in most of their earnings going into medical expenditure. The BHV identified two children aged 6 years (boy) and 8 years (girl) as suffering from TB, having contracted it from the father. They received the DOTS medication and are now successfully treated. Recently, with the help of the BHVs, one female got diagnosed for TB and is receiving treatment under DOTS. She has also started receiving Rs.500 for supplementary nutrition support, which many families had failed to get. Almost every family has debts related to health expenses. Of the 13 families, 5 are widow-headed, whose distress situation led to their children dropping out of school.

**Madaiyan village** has 52 ST families from Raj Gond and Nand Gond sub castes. The Nand Gonds are the most vulnerable and

have very little land. Considerable extent of land was lost for the PTR, both revenue patta lands and forest lands eligible under the FRA. None of the families received any compensation nor IFR pattas although claims are pending. A number of Gond families have a long history of working in the stone mines, and a few families continue to depend on mine labour near Panna even today. The men, including young boys, migrate to places like Pawai in Panna district where extensive stone mining continues. Despite being diagnosed and undergoing treatment for TB, the men continue to work in these mines for lack of any other labour locally. From recent medical tests conducted, four men are confirmed as having TB and Silicosis and 3 men have been confirmed as having TB. In this village there are 16 Gond widows, all of whom lost their husbands to either TB or Silicosis. In 2022, two persons succumbed to TB and Silicosis. There are 9 children in the age group of 6-15 who have dropped out of school, helping in the household chores, working

in agricultural fields, loading water in the Panna water treatment plants, and migrating along with their adult family members seasonally to Haryana, Mathura, Surat and other places. Their work is hazardous, strenuous and toxic, no matter what field of daily wage labour they choose - construction, textile mills, mining, agriculture, timber-mills, or other industries. Youth who migrate earn short term high incomes but the strenuous work results in alcoholism, chewing of tobacco and within a few years, TB, suspected HIV and Silicosis. One youth who worked in the furniture factories, lost his vision due to the hazardous work. Women are also regularly migrating with their husbands and performing tasks like sifting and carrying mud in the illegal diamond mines or in harvesting wheat, sugarcane and other daily wage labour. Adolescent girls also accompany their families to work in these activities. Locally, they gather NTFP like Mahua, Amla, Chironjee and firewood. However, due to increasing

tiger population, their area of foraging in the forest has considerably reduced, and so also their incomes from NTFP. This village experiences frequent cattle deaths due to wildlife attacks, with no compensation reported by most families whose cattle died. The immediate effect was out-migration and resultant health problems. Women have the double burden of walking to Panna in search of daily wage labour while the workload in the house has also doubled due to water distress, lack of access to wild food and firewood and the increasing burden of care-giving for patients in their families.

**Kaimasan village** is on the border of the PTR core area and the NMDC mining, with just a wall separating the village, where many families lost their agricultural land. As they do not have pattas for these forest lands eligible under the FRA, they did not get any compensation for the land lost. There are two mohallas both together having 82 families of Nand



*Kaimasan village. Beyond the field (the cluster of trees in the background) is the core area of the tiger reserve.*





*Women using cloth to filter water from the handpump in Kaimasan village*

Gond, Sor Gond and Sonkars (SC). The upper castes from Bador village, they claim, cause violent disputes and prevent the Gonds from accessing their own lands or even putting up claims under the FRA. The village is located very close to the NMDC diamond mines and suffers from water pollution and biodiversity loss like drying up of streams, talaabs (tanks), extinction of fish species and herbal medicines that were their source of nutrition, death of cattle from drinking polluted water or being killed by wildlife attacks. This village particularly faces a constant threat of wildlife attacks with every family having lost their cattle, and with no compensation received. No family has any hens, goats or cows any more which were earlier their source of nutrition and income from sale of dairy products. They say that the drinking water pollution is severe due to diamond mining with the two hand pumps that are the only source of water, spewing contaminated water. So women have to find other means of cleaning the water or walk longer distances to other sources, adding to the burden of their workload. The ASHA worker herself is directly affected

by this contamination as her young daughter of 5 years is reportedly suffering from a rare congenital kidney disease which the doctors apparently told her was due to water toxicity. Nand Gond, Sor Gond and the Sonkars are very vulnerable communities with malnutrition and disease universally present in every family. In this village, 1 person has a patient registration card which indicates Silicosis and TB and 4 persons have been diagnosed with TB. One person died in June 2022. Although it is a directly affected village by NMDC company, none of the promises made for employment to the Gonds, were fulfilled. With loss of land and forest resources, seasonal migration has increased. There is no job card or MGNREGS work under which the Gonds are employed. Entire families leave for Haridwar, Surat, Mumbai and Delhi. Of late, the youth are also going to Ladakh for construction work. Here Gond women migrate with their families to work in the stone mines at Pawai as there is no livelihood opportunity in the village. We do not have an assessment of the women's health condition among those working in the mines. Domestic violence and

alcoholism are very high due to addictions as a way of coping with the health problems, migration and financial tensions of mounting debts. But the community is unable to help the women who face daily physical abuse and financial burden. Almost all the men work in the mines or other construction labour and consume high doses of different substances, as otherwise, they cannot sustain the hard labour in the mines. Two children dropped out in 2022 but others who had dropped out were re-enrolled in school with the efforts of the barefoot health and education teams.

**Bador** is a panchayat village with approximately 230 families, consisting of a mixed population of tribals and non-tribals. The tribal families belong to Sor Gond, Nand Gond and Raj Gonds with an approximate size of 122 families. Very few tribal families (17) received FRA pattas and only for small pieces of land, while the large majority of

families are awaiting settlement of claims. Only 11 Gond families have revenue land and they cultivate mustard, wheat, chickpeas and lentils. Only 3 villagers from the upper caste got employment with NMDC, but not the Gonds. The Gonds are exploited by the upper caste on several matters including corruption in wages from MGNREGA, as complained by the tribals. There is a history of mine labour among the Gonds who have worked for many years in the stone quarries. There are stone quarries present in Bador itself, although officially they are closed and Gonds are hired as mine labour now and then, by local contractors. They also go to Shahnagar and other places in M.P for similar stone breaking work. Almost every tribal family goes out for migration seasonally to Surat, Chhattisgarh, Jaipur, Maharashtra, Sagar, Gurgaon, Bhopal, Indore, Nagpur, Jhansi, Haridwar and other places for construction work, brick kilns, restaurants and small shops and other petty



*Women returning after collecting firewood from the forest*

daily wage labour in small scale industries. Women and children accompany the males, and this year, our survey showed that 17 children are out of school, disturbed by the constant migration. Women and children help in all the above activities at migration sites. There are 32 widows who mostly lost their husbands to either TB or Silicosis or both. In Bador, 10 persons have been diagnosed with TB and 2 persons with both TB and Silicosis, after a recent screening at the PHC. One of them is a female. There are 4 orphan children here as parents have died due to multiple health problems, suspected to be linked to TB and Silicosis. These children are now living with their grandparents. Two children have only an aged grandmother to take care of them who is unable to pay for their fees and education expenses. So she has made them drop out of school. Neither of the grandparents have old age pensions nor proper ration card support and hence the minimum social security entitled to them is also absent. The education volunteers and BHVs assisted these children in getting school admission again last year.

**Darera** in Manor panchayat is a large village with a mixed population. It has 72 Gond families. They are directly affected by the PTR and lost agricultural land as well as access to the forest. They are eligible for land titles under the FRA, but the FRC has not been formed and the tribals have been unable to put up claims due to non cooperation of panchayat officials. In the past, many tribes worked in the stone mines, and some continue to do so even today. There are 5 reported cases of TB here but despite the DOTS treatment, they have not been cured. The men casually mention that they take alcohol as their only resort to deal with the problem as they have to continue daily wage labour. There are 18 widows in this village, most of whom lost their husbands to TB and Silicosis. So far, women have not come forward to undergo diagnosis for any ailment. One female was diagnosed with TB and underwent the DOTS course, but continues to suffer from the disease, has severe

cough and body pain. Access to NTFP is limited due to the PTR. Neither are they allowed to sell the NTFP even if they collect any produce as the forest staff prevent them from collecting and selling any forest resources. The women resort to the only source of income they have - by stealthily collecting firewood and selling it in Panna town. But this is not often or easy. Therefore, the entire Gond population, including women and children, go for seasonal migration to places like Kanpur, Delhi, Gurgaon, Hyderabad, Surat. The Gonds are experts in stone breaking and hence are taken by the agents to places like Kotraya and nearby stone mines. In Darera village, last year in 2022, at least 23 families went for migration leaving behind only the elderly. This is reflected in the absence of children from school, especially after class 7 and 8. None of the girls go to school as they all go for migration. Girls also find it unsafe to walk to high school due to lack of transport and the presence of non-tribal males along the way. In a household survey conducted by us, we found 18 children out of school who were helping their families with house work and odd jobs at migration sites. The Gonds here have serious difficulties in getting covered properly under social security schemes like ration cards, Aadhar cards, job cards and pensions. They complain that local panchayat officials are not helpful and extract money for every correction in their identity cards. Although there is a road, as the forest department prevents any development activity citing threat to the tigers, none of the schemes are properly implemented here, including MGNREGS. The only way of survival for this village is to go for migration and they return every season with chronic health issues like TB, malnutrition and suspected Silicosis. The entire village regularly migrates to Rajasthan, Gujarat, Delhi and other places, mostly for mine labour. The other villages included in this study are relocation sites, with similar stories of loss of access to their lands and forests, and the loss of livelihood resulting in persistent migration. One has to follow

their cycles of migration in order to locate them and get them tested for these two illnesses. We are still in that process of identifying and motivating the families to reinstate treatment for TB and to get themselves, at

the least, certified as having Silicosis. Loss of access to their lands and forests, and the loss of livelihood are reported as the major drivers for migration from Panna.

**Table 7 - Seasonal migration**

SI No	Village	Total ST HHs	ST HHs who migrated in 2022
1	Bador	122	54
2	Darera	72	23
3	Kaimasan	46	6
4	Madaiya	52	10
5	Umravan	13	6
6	Hirapur	75	34

**Table 8 - MGNREGA facility availed by STs in Bador panchayat in the year 2022-23 reveals low rate of employment guarantee to ST families**

Name of the village	Total ST population (as per census 2011)	No. of ST members who got jobs in 2022-23	Total no. of days of work
Bador	433	73	3227
Umravan	100	1	12
Kaimasan	238	7	222
Madaiyan	255	18	156
Total	1026	99	3617

**Source: Ministry of Rural Development, Government of India**

## 4. Widows and Caregivers of Panna: Personal Narratives

Working with the Gond Women of Panna, most of whom are widows and suffering from the economic burden of being the sole breadwinners for their families, while they watch their husbands and sons wither away in front of their eyes with the wracking pain of Silicosis and TB, we find that most ignore their own physical and mental health, a privilege they cannot afford. Talking to these women we found that most of them have malnutrition or symptoms of TB/Silicosis like cough, blood while coughing, body pain, weakness, chest pain etc. Imarti Bai, Kirana and Rajkumari, for example, are widows in Panna, and while they are the lucky few who do get the TB stipend, it is not enough to run a household. Government support is barely felt by them. They either must build makeshift houses themselves (Rajkumari) or live in the shelters provided for by the contractors they work for (Imarti bai).

The forests do not provide adequate resources to meet all their requirements and living near the mine sites runs the risk of aggravating their respiratory problems. The complex challenges of coping with eviction from the national park and the long history of mine labour have compounded their present crisis and, even after more than 15 years of being relocated or readjusting to resources lost, the social, economic, medical and ecological impacts are most severely experienced by these women.

We bring here some stories of women (and girls) survivors, care-givers and bravehearts who are fighting daily battles with TB, Silicosis and a host of social and economic challenges. Whether that of Kirana and her three children who were thrown out of their house after the husband's death, or of Roshni who struggles to take care of her infant while try-



*An elderly caregiver sharpening her axe as her grandson looks on*

ing to cope with her illness, these women are knitting together their collective agency in the community, but much needs to be done from the outside.

### **Geeta Bai, Hirapur**

Geeta Bai, 38 and Chotu, 40 are a Gond couple displaced from Umraivan for the PTR in the year 2015 and they are now living in Hirapur. The couple stays with a 70 year old mother, a newly married 19 year old son, 18 year old daughter-in-law (Saraswati) and a 12 year old daughter. Manjhali Bai, Chotu's mother gets no pension and has to work as a daily wage labourer for her sustenance even at this old age, as both her son and daughter in law are TB patients. Her daughter in law and grandson also work with her but they only get a few days of work in a month, hence their monthly income per person is only around Rs 1,500.

Both Geeta and Chotu worked earlier in stone mines, when they were just 15-16 years of age. Chotu worked in a stone mine for 15 years, while Geeta Bai worked for 5 years. They do not remember using any safety equipment or getting proper wages. Now both of them are sick. Geeta is diagnosed with Tuberculosis for the last 12 years, while no proper medical examination was done for Silicosis. She has been repeatedly going through the DOTS programme in Nawagaon, but with no effect. She has developed MDR and is reluctant to go through another course of DOTS, her condition being very fragile. Chotu has been unwell for the last 3 years with Tuberculosis/Silicosis like symptoms - cough, stomach ache, weakness, loose motions, etc. Even in this condition he migrates to Khajuraho, which is 45 kms away for at least 60 days in a year, as a construction worker.

In Hirapur, the Gonds have no source of sustenance. Back in their native village Umraivan, most of the displaced families had some amount of land either revenue or forest land,

livestock, mahua trees and access to several NTFP varieties for their income and food. Women didn't have to walk 1.5 km for every drop of water as they have to, today. Chotu and Geeta Bai also lost 1.7 acres of revenue land for which they got compensated with 2 lakhs from the forest department. In Umraivan, they had 3 goats and a cow but now they have none since there is no fodder available to feed livestock here. Hirapura is surrounded by CAMPA plantations with restrictions on local communities for collection of any forest produce, or even firewood. So now when Geeta doesn't find work, she goes (stealthily) to these plantations to collect dried bamboo for cooking and for selling it. She goes to the forest at 5am to collect bamboo and returns back at 10am. Only the next day can she take it to the market and earn an average income of Rs 60 every alternate day. Even though these families have settled in Hirapur in 2015, they neither have property documents for their house nor do they



*Geeta Bai with her TB medicines*

avail of any government documents/entitlements, not even ration cards or voter ID cards as their proof of residence in Hirapur. As the colony is away from the main road, a patient has to walk 1½ km to take a bus and travel 100km to reach Nawagaon TB hospital or 35 km to reach the government hospital in Panna.

Having no property or source of income and with the prolonged disease, this family is in a distressed condition. Geeta Bai goes to Nawagaon for TB treatment every month. She has already spent around 1.5 lakh rupees and has completed the DOTS course with no effect. She now refuses to take the medication despite the BHV's appeals to her, as she is too weak and unwell to handle the drug. The family is in debt, having borrowed around Rs.50,000 from the farmer for whom Geeta works, and another sixty thousand from a moneylender by keeping her jewelry as collateral. There is constant pressure from the money lender for repayment. All this burden has passed on to the newly wed couple, Anil and Saraswati. Anil is a school dropout and has succumbed to gutka and alcohol, in his journey of working as a child labourer to support his family. His wife Saraswati, at a very young age, became the main caregiver for the family. Geeta Bai herself helps in caregiving and other household work as well as paid work. She goes into the forest early in the morning, fetches water from 1½ km away, cleans the house and also cooks food. Household work is shared by Saraswati who is now pregnant. Saraswati cooks separate food for both patients, mostly boiled food like Spinach, Moong ki dal(yellow lentils) etc as well as washes their clothes.

It is quite difficult for Saraswati, the daughter in law, to go through all this at this young age. Even if she is pregnant she can hardly afford fruits or nutritious food. She hardly takes proper rest, except when she is really sick, as her mother in law is already unwell and the burden falls on her 12 year old sister in law to take care of everyone. Mentally

they are having a hard time though neighbours do help them sometimes in terms of lending money or food. The neighbours are all living in a similar condition, having been displaced from their village and constantly rushing for migration to other states. Saraswati and the 12 year old girl also help the grandmother with her cooking, fetching water and firewood.

### ***Punia Bai, Hirapur***

Punia Bai, 50 years old wage laborer also settled in Hirapur in 2015 after the forest department displaced them from Umrawan for the PTR. Punia Bai stays with her 58 year old husband, Lakhan and two sons. None of their family members ever worked in stone mines but three of her family members including herself, her husband and their 16 year old son Chandrapal, are suspected TB/Silicosis patients for the last 5 years. Lakhan, her husband, has had a cough and fever for the last few years while Punia Bai for the last 2 years. She complained about medical expenses since she and her husband work at construction sites and getting sick means no work as well as extra burden of medical expenses. This year the family spent fifteen thousand rupees only for Lakhan's medical expenses.

Before coming to Hirapur, Punia claims that the condition of the family was better. They had 2 acres of land, 2 cows and collected NTFP worth Rs.40000 each year. They also had access to wildfood, vegetables and medicinal herbs. But once they shifted to Hirapur they only have bamboo as a resource, but which has to be collected 'illegally' or they have to migrate elsewhere searching for construction labour. Punia Bai tills some land of another farmer but she has to share fifty percent of the harvested crop to their landowner, leaving very little for their own family sustenance. She wishes that she had not left her land in Umrawan.

Punia Bai is a farmer, constructor worker, and



*Punia Bai being interviewed by our team as part of the survey*

care-giver. She is doing care-work as well as work as a labourer. When she is not farming or doesn't find work at a construction site, she collects dry wood from the nearby forest and, if she is able to sell, then she earns around Rs 100 a day. Punia Bai cleans her house, cooks food for everyone, goes to the forest sometimes, takes care of her husband and goes to the farm during sowing season. When asked about a nutritious or balanced diet, she replied that they don't have enough money to have a choice if it's nutritious or not. Her son, Chandrapal dropped out of school to meet the family's survival needs and now works as a wage labourer. The family took a loan of Rs.50000 from the micro finance agents. Punia Bai's family doesn't have any government documents in Hirapur and, even for PDS rations, they have to go to Umrahan which is 50 kms away, to collect the ration in the months they get it. She is highly distressed and nervous, just like the other displaced women of Hirapur.

### ***Phulmati, Hiralal's 80-year-old Mother, Darera***

Hiralal, 60 years old, was a mine worker from Darera village. He has been diagnosed with Tuberculosis 20 years ago and has been suffering since then, with persistent cough, chest pain, fever and weakness. Hiralal's illness is not all of a sudden. He worked in the stone mines as a mason for 35 years. His work involved breaking and cutting stone into different sizes. He started working at the age of 15 and worked even during the first 10 years of TB being diagnosed. He lives with his 80 year old mother, Phulmati, in a dilapidated house and whose only sustenance is a monthly (erratic) pension of Rs.600. Hiralal is getting treated at a private hospital in Nawagaon, 90 km away from Darera. He spent approximately Rs.1 lakh for his treatment till now, but is still unwell. His aged mother also complains of body pain, swelling, back and knee pain and is unable to walk. Yet, she is his sole care-giver.



Hiralal has 5 acres of revenue land but due to illness he has given his land to a tenant farmer, who pays him a fixed amount of Rs.7000 annually. He doesn't collect anything from the forest any more and has to purchase firewood too as neither he nor his mother are in a condition to gather wood. When Hiralal is too unwell, they call some relatives to help him visit the hospital as his mother can no longer walk much. Phulmati is dependent on the children in the neighbourhood for fetching water or going to the shop. Even in this aged condition, she does all the household chores of cooking, washing their clothes and cleaning. She is hardly able to clean the house regularly. She says that it would be impossible to survive without help from neighbours since they are the ones who take him to hospital or call the ASHA worker if they cannot go with him. As a caregiver Phulmatibai doesn't have the luxury of taking rest even on days she is not well or is too tired to cook as she has to take care of her son. Sometimes her grandchildren take care of her. She is mentally exhausted with all this burden in her life, from her son's illness and her own ill health. She finds it stressful to constantly seek help from neighbours or find financial assistance whenever they need to go to hospital. She also worries that if she dies there will be no one to take care of her ailing son.

### ***Sunita, Darera***

Sitaram, 57 years old, lives with wife, three sons, three daughters-in-law and four grandchildren in Darera village. Sitaram and his family members are all landless wage laborers from the Sore Gond tribe. None of the family members throughout all three generations have ever been to school and most of the adult members except for Sitaram who is too ill to travel, migrate for work to Rajasthan, for about 5 months in a year. They migrate as a group, all three sons and their wives including children, go together for 5 months. Only Sitaram and his wife stay in the village, and with no land, Sunita Bai works as

a daily wage laborer as well as takes care of her husband, diagnosed as a TB patient, but it is not clear whether he also suffers from Silicosis.

Sitaram earlier worked as a mason at a stone mine for at least 30 years. He started working when he was just 22 years old. In the last five years he started getting TB symptoms like cough, chest and thigh pain. He even took the medication (DOTS) given by the ASHA worker of the village and currently he is getting treated in Panna government hospital although the DOTS course has ended. During the migration period when his other family members go to Rajasthan for work, he is dependent on the ASHA worker for taking him to hospital. The family doesn't have land but each year they collect NTFP worth Rs.30,000 from the forest, which they use for Sitaram's medical expenses. Now his son Arvind is also having some symptoms like body pain, fever for long durations and persistent cough. The family does not have any of the government entitlements except for ration cards. Sitaram says he did not even receive the monthly Rs.500 given to TB patients for supplementary nutrition.

Since all the sons and daughters in law migrate for work, the entire household burden and all the caregiving work is taken by Sunita, Sitaram's wife. But Sunita is also getting old and unable to cope with the responsibilities. When the daughters in law return from migration, they do help with most of the work. In a day, Sunita does all the household cleaning work, cooking, serving food to her husband, then goes into the forest to collect firewood and also tries to find paid labour work, if she can find any. Sunita's daughters in law have heavy work loads and are themselves malnourished. One daughter in law shared that she has irregular periods and feels very weak as she doesn't get any rest even if she is unwell. Her husband doesn't help her much and as they have very meagre income, she says she avoids going to the hospital or buying any medicines due to lack of money.

With the son also showing symptoms, the young wife is also worried about her future situation.

### ***Badi Bahu, Madaiya***

Dasarath Singh and his family live in the village of Madaiya located near the Panna National Park. They survive on around Rs. 6000 per month. With six mouths to feed and a significant amount of debt, it is not uncommon for them sometimes to either go hungry or make do with very little food. Within that amount, the entire household has to be managed. With healthcare taking up the majority of their expenditure, the expenses on food and children's education are highly compromised. The family owns no agricultural land and are dependent on remittances from the two eldest sons who work as migrant laborers, traveling as far as Haryana for 6 months out of a year. The family does not have much else, except for their house and a buffalo. Like all other families in the village, they depend on the forest to fulfill a number of their household needs such as firewood

for cooking and various other NTFP like Mahua and Chironji. Their situation is one of extreme poverty and deprivation aggravated by the health condition.

Dasarath Singh has been suffering from an undiagnosed sickness whose treatment requires additional health expenses and special care. There is a possibility that he could actually be suffering from Silicosis. This is evidenced by the fact that the doctors have said that his lungs are filled with dust and, with his history of working in a stone mine for more than 10 years, we can come to a reasonable conclusion that it is an undiagnosed case of Silicosis.

Dasarath Singh who is now 40 years old and looks much older with worn out features, started working in a stone mine when he was just 15 years old. The stone mines in the region are largely operating illegally. The stone miners work long hours in extremely exploitative conditions doing backbreaking work with no safety protocols. In these conditions, it is not surprising that Dasarath Singh started having respiratory issues around 8 years



*Badi Bahu being interviewed by our team as part of the survey*

ago. He was able to work for a few more years after coming down with the sickness but, after a point, he could not work anymore. With the only source of income for the family vanishing, his children, who were teenagers by this time, dropped out of school and began working as wage laborers. They started out working in nearby areas at first and then began migrating seasonally to other states like many other youth in the village, sending back most of the money they earned.

Despite all the treatment, Dasarath Singh has not recovered fully even after 8 years, largely due to misdiagnosis. They had to travel 50 to 100 km every time his situation took a turn for the worse, to get treatment. The nearby government hospital at Panna was not equipped for treating him and local health services near his village, especially the ASHA worker, does not have the training or the time to deal with an illness such as Silicosis. They have not received any nutrition kits or any compensation either for Silicosis or even tuberculosis.

The effect that Dasarath Singh's sickness has had on his family is invisible and intangibly agonising. They have been dealing with extreme poverty, hunger and constant emergency care. Yet they manage to survive and live in these conditions. This is mostly possible because of his wife Badi bahu, who stepped into the role of managing the household including the finances along with being a caregiver to the patient in the family. She held the family together with sheer strength and determination and brings the family out of the darkest of days, each time they face a crisis.

Badi bahu says that when her husband fell sick and the income dried up, she began working as a manual laborer and earned Rs. 400-500 per day to keep themselves out of hunger and to buy the medicines required for him. This is on top of doing the house work including cooking, cleaning, etc and taking care of her sick husband. She took him to the

hospital multiple times for treatment and stayed by his side through his worst times. She says that she had to deal with increased workload in terms of preparing food separately for him without any spices according to the instructions of the doctor and dealing with the psychological stress of the situation. Though later her daughter began helping her manage the housework, the boys were not of much help there.

She also had to borrow money from her relatives and the money lender which they are still paying off. She laments how the education of their children was cut off and how they will not be able to move upwards economically. Even though her family was supportive, due to the stigma of the illness the family became isolated. But even with all this, she says that she never lost hope and managed to survive each emergency.

### ***Nimiya Bai, Kaimasan***

Nimiya Bai is a 70 year old elderly woman living in the village of Kamaisan. Her husband passed away 3 years ago with suspected TB/Silicosis. She is currently living alone taking care of her 2 grandchildren as her son and his wife are in the city of Gwalior working as migrant laborers. She wakes up everyday, cooks and cleans the house, gets the children ready for school and then goes into the forest to collect Mahua seeds, firewood and anything else that is required for the household. With the village situated inside a tiger reserve, many villagers are afraid of going into the forest for fear of attacks by wild animals. But Nimiya Bai is unafraid and goes deep into the forest by herself to gather various forest produce. She says that she has been going into the forest since she was a child and no tigers or bears will stop her from going in there. She also says that the forest belongs to her and the people living here and it is their right to go into the forest no matter what the government or the forest department says. Part of her livelihood comes from selling the Ma-



*Nimiya Bai*

hua seeds that she collects and which fetch around Rs. 7000 to 8000 in a year.

She also owns a portion of agricultural land where the family cultivates wheat and mustard. But they only cultivate the fields once a year in winter when her son comes back to the village. What they produce is somewhat sufficient to survive along with PDS rations, that leaves them with a little extra produce which they sell in the local market. However, farming is getting extremely hard here due to groundwater depletion (she suspects it to be the effect of the diamond mines closeby), and the increasing crop attacks by wild boars. The struggle for space between an increasing tiger population and other wildlife in the forest is driving more predatory animals into their farmlands, as narrated by Nimiya Bai and others. Sometimes almost half of their cultivated crop is destroyed by wildlife, and the certainty of harvest is fading from these poor farmers' lives. When there is insufficient rainfall, like it has been happening for the past few years, the losses in agriculture add up to their woes.

Nimiya Bai's husband had worked in a stone

mine for more than 40 years starting in his 20's and he was sick for almost 17 years before his death. The symptoms included coughing, chest pain and difficulty in breathing. Even though these symptoms match those of tuberculosis (which Silicosis is usually mistaken for here in this region), his long history of work in the stone mine along with the fact that these are illegal mines with workers being provided no safety equipment, strongly indicates that it is Silicosis. She says that they went to multiple government hospitals in Panna and Nawagaon but the best that the doctors could tell them was that he was suffering from weakness and the medication prescribed was for treating the symptoms like cough. To escape from the pain Hira Lal began drinking a lot and that made the condition worse. Ultimately after being sick for so many years and being confined to the bed unable to breathe properly, he passed away.

Hira Lal's prolonged sickness had an enormous impact on Nimiya Bai and her family. Their son Gaj Raj had to drop out of school and start doing manual labour to earn money after his father became too weak to work anymore. The family had to take large

amounts of loans from their extended family to take care of the healthcare and travel expenses through all these years. In the course of all this, even the son fell sick and the sickness has not been properly diagnosed till now. Nimiya Bai during all this time, was the only one taking care of the entire household and taking on the role of caregiver for her husband. She made sure to give him medicines on time, help him move around, bathe him, take him to the toilet outside and generally watch over his condition. She says that all of that created enormous mental stress for her as she watched her husband wracked in pain and wither away in front of her eyes and she could not do anything to stop it. She also went hungry a lot of days when there was no food, prioritizing her husband, her son and the grandchildren and consequently fell sick herself. Along with this she also took care of her son and took him to the hospital whenever he was seriously ill. She had to prepare food separately for both of them and without any salt or spice. This created an additional burden.

They try to get some support from the village but as many others in the community are

also sick, everyone is struggling to cope with the ill health in their own houses. They also did not receive any support from the government in terms of compensation for illness or even a proper diagnosis.

Through all of this, the family persevered, even after the death of Hira Lal, with Gaj Raj and his wife becoming migrant labourers traveling far from home for many months each year, to earn a living. They also sometimes take their children with them leading to their education being disrupted. Nimiya Bai herself was quite distraught after her husband passed away, not being able to do anything. But gradually she picked herself up and went back to her old routine of waking up early in the morning, cooking and cleaning the house and then going into the forest to collect Mahua seeds and taking care of her grandchildren.

### ***Kirana, Bador***

Kirana, aged 40 years, is a widow living in Bador with her three children. Her husband, from a distant village, had succumbed to TB



*Kirana*

despite following a proper TB treatment regimen. She and her children were thrown out of their house by their relatives who blamed her for his death and threatened to “kill them if they ever tried to come back to the house”. Kirana returned to her native village with her children. Later she too contracted TB and as she said, “I got extremely sick and weak”. The situation is so dire that she “cannot even walk let alone cook a meal for the kids”. They don’t have a pukka house to maintain any distancing between herself and her children. She has to cook food for all of them. The older son is working in a provision store and the other son is doing construction work as she is now too ill and cannot take care of the family. The two sons had to drop out of school to take over their sustenance. The youngest goes to school and is under constant threat of having to drop out too. Kirana’s care is completely in the hands of her three sons and she says that “they try to give her nutritious food but it is always not possible to cook separately, so sometimes she has to eat spicy food that irritates her stomach and causes a lot of pain.” She is undergoing treatment in Satna and has almost completed the DOTS course. Yet she is too weak to work and feels extremely guilty that she has to depend on her children.



***After my husband passed away due to TB, my in-laws blamed me for his death accusing me of not taking proper care of him. They cut off all ties. Now, when I have TB, my sons are the only support I have.***

***- Kirana Bai, Bador***



### ***Kamala Bai, Bador***

Ram Singh lives in Bador village. He used to work in a stone mine until 4 years ago when he came down with an illness. When he went to the doctors he was informed that he had contracted Tuberculosis. He has 4 children and all 6 of them including his wife live in a small house in the center of the village. After his diagnosis life became significantly more difficult for him and the entire family.

The only source of income in the family used to be Ram Singh’s job in the stone mine. But after he fell sick and could not work any more, the family fell into a crisis. One of the sons dropped out of school to search for work but could not find anything. The family does not own any land, so they cannot depend on farming to get them through the lean times. They also do not own any cattle. There were days when they went hungry because there was little to no food to go around. They even went into heavy debt as they had to borrow money to pay for Ram Singh’s treatment. There was a possibility that they might end up destitute and lose their home. This is when Kamala Bai, Ram Singh’s wife took matters into her hands and started selling the firewood and Mahua that she collects from the forest. After this, for the past few years they have depended entirely on Kamala Bai and on the forest to live and survive.

The treatment for tuberculosis lasts for about 6 months after which the disease is supposed to be eradicated. But Ram Singh has been suffering with his affliction for more than 4 years even after going through multiple rounds of Tuberculosis treatment costing more than 30000 rupees, which is an extraordinarily large amount for him. This is the first piece of evidence that points to the fact that he may have been misdiagnosed. The second is that he has a history of mine work going back 15 years probably in unlicensed mines, as he has no proof of employment and safety protocols were nil. They live in a very small

house with no segregated spaces for the ill. He may have been suffering from both TB and Silicosis, given his persistent illness.

Even though he was diagnosed with tuberculosis and underwent the DOTS treatment, he never received any compensation or pension from the government. He also says that the ASHA workers never paid a visit to his house to guide the family on how to deal with the disease. They even had to go to a private hospital in the town of Nawagaon, 100 kms away, for treatment as the government hospital in Panna did not have the doctors or the facilities to treat him properly. This is the reason for the extraordinarily high cost of treatment. They still managed to raise the money as Kamala Bai is a member of a local women's self help group. She borrowed the money necessary to pay for the medicines and for the multiple rounds of travel to and fro to the hospitals, and also to run the household, for food and other necessities.



*Ram Singh*

Kamala Bai says that it has been extremely difficult for her since her husband fell sick. She is the one who takes care of the entire household and does most of the housework including cooking, cleaning, laundry and taking care of the children, although some of this work was taken up by her daughter. The men and boys of the household do not contribute to the house work at all. Along with housework and daily wage labour, she has to provide care to Ram Singh by giving him medicines, helping him move around, providing emotional and mental support and making food specially for him such as using moong dal, fishes, green leafy vegetables collected from the forest etc cooked in a way that does not exacerbate the disease.

All in all she says that it has been a tough few years that they have faced. And the ordeal is still not gone as Ram Singh is far from recovered. The new course of medicines are working but she says that once the course stops, the disease comes back and his condition becomes severe again. She says that they have received much support and assistance from their family but nothing from the panchayat or the government.

### ***Lachchu Lal's teenage daughter, Kaimasan***

Lachchu Lal, aged 48 years, is from Kaimasan village. He has been a mine worker since the age of 18 and worked for more than 15 years, shifting from one stone mine to another. He is a widower, having lost his wife eight years ago to an undiagnosed illness (possibly TB). He has two sons and one daughter. The sons live separately, and the 17 year old unmarried daughter is his sole caregiver. Since the last 15 years Lachchu Lal has been running around for treatment and resorted to both government and private clinics with multiple rounds of medication and says he has incurred at least 7 lakhs (0.7Million) as expenses in all these years. Yet there was no relief and he now lies like a frail limbed object on



*Lachchu Lal being interviewed by our team as part of the survey*

the bed, unable to walk or sit. His daughter who takes care of him all by herself, has been persisting with her studies, despite these challenges, and is now in Class 12. The sons try to help with money, but she has to find work for basic sustenance, go to college and take care of all the house work and care work for her father. All her jewelry and her mother's jewelry, whatever left of it, is mortgaged for their daily expenses. The BHVs took him to the PHC and he is now diagnosed with both TB and Silicosis. But he has neither faith in the medicines nor hope of recovery as he is too ill to withstand the powerful medicines. He has completely stopped taking all medicines and struggles with his condition, his sole asset being the Silicosis Certificate from the government. He has stopped taking any alcohol or gutka now and is careful with his diet.

### ***Jibbu, Bador***

Jibbu is from the vulnerable Sor Gond tribe in Bador village. He is 55 years old as per the Aadhar card, but complains that he is older and eligible for old age pension which he is being refused due to wrong entry of his age

in the ration card and aadhar card. He never owned any land. When he was 20 years old, he started working in the stone mines and worked for 20 years. His wife worked as an agricultural labourer and is also aged and fragile. However, ever since he has been sick for the last 15 years, she has been taking care of him and has the entire burden of going for agricultural labour, which is not regular. She somehow manages to find daily wage



*Jibbu (wearing blue)*





*Roshni*

labour as her income is the only source for his medicines and food. He has been a TB diagnosed patient, receiving treatment from Nawagaon, on and off. This erratic nature of undergoing treatment and discontinuing for the sake of migration or ignorance about follow-up treatment, has been a common reason for recurrence of the disease. This has been the case with Jibbu as well who stopped taking the medicines once he got relief. Now he has become resistant to the TB medication, but he still continues taking a fresh round of the DOTS medication. Jibbu stopped consuming all substances and came out of his addictions. His wife makes sure he takes his medicines and food regularly.

### ***Roshni, Kaimasan***

Roshni, 19 years of age, is from Kaimasan village. Her father was landless and worked as a mine worker in different stone mines. He had a prolonged history of TB and he finally died in May 2022. The family has to depend on construction labour and migration. Roshni was married off to a man from another village at the age of 19. She contracted TB prob-

ably from her father, although the doctors have not given a clear diagnosis. She is extremely unwell and not in a position to even walk or sit. She is so weak that she often cannot “get out of bed and do basic household chores or even go to work”. Suspecting her to be a “burden”. Her husband’s family refused to take care of her or bear the expenses for her treatment. They often beat her and denied her food as she was an added burden to their poor earnings. Unable to bear the violence, Roshni took her infant daughter and returned to Kaimasan. She now lives with her mother and siblings who have no stable source of income and cannot get her the appropriate treatment. They have already taken loans for her treatment and are in heavy debt. They are constantly fearful that she will meet the same fate as her father. Unable to see her condition, the BHV has referred her to the PHC and local private hospitals too. But there is no proper diagnosis given nor treatment as the doctors are unable to identify the actual cause of ill-health. She continues to live in the village, with no support and somehow does some odd labour work to take care of her daughter. Kaimasan is under constant threat of eviction as the village

is on the boundary of the PTR. Single women like Roshni live with the constant fear and anxiety of eviction even while their physical and financial condition is already extremely fragile.



***Following the death of my father due to TB, my mother is the sole breadwinner in the house. She goes out for labour work and also tends to our fields. My younger brother and sister are currently studying. With her earnings, my mother has to take care of the education of my siblings, my health, and even my daughter.***

***- Roshni, Kaimasan***



### ***Kishore Singh, Madaiyan (death in December 2022) and 13 year old Amrita the care-giver***

Kishore Singh, was a widower. He lived alone next to his son's family in one corner of Madaiyan. Even though their houses are beside each other, he lived by himself in a small kutcha house abutting the larger pucca house belonging to his son. He had worked for over 40 years in the stone mines because of which he was sick for the past 20 years. He has three children, of whom one is mentally unwell. As the other members of the family could not

cope with the mental illness, Kishore Singh was taking care of his son alone, although he himself had chronic health problems. It was his 13 year old granddaughter Amrita, who was providing the additional care and support, with small chores like fetching water and getting firewood. She took care of him when he was really unwell, helped with the cooking and washing, getting firewood and in giving him medicines. Although he was suffering from suspected Silicosis for a prolonged period, the diagnosis from the doctors had also been inconclusive. He was treated for TB multiple times, but to no effect. He had to stop working in the mines due to his illness and survived on the TB pension of Rs. 500 per month and a small patch of land he tried to till. It was not easy as he had to single handedly dig out a well in order to have water for irrigation, but eventually had no physical strength to cultivate the land. Kishore Singh was very knowledgeable on the forest and local herbs. The villagers often approached him for herbal remedies. He used to go into the forest regularly to collect all types of leaves, roots, seeds, wood and other resources both for making medicines and also for food and other household needs. His eccentricities are well known in the village and he used to regale the children with tales of the village and the forest.

He also followed a very strict diet, gave up alcohol and other substances and led a very disciplined life, treating himself with his herbal medicines. Kishore Singh had set an example of self-care by ensuring, despite all the poverty, to maintain his diet, sustain on his traditional knowledge and somehow manage to cope with the illness. He motivated others to give up substances, dispensed with his medicinal knowledge to other patients and was well respected. Yet the severe condition of his lungs and the long years of heavy work in the mines took its toll on his health, and in December 2022, he succumbed to the illness, fighting it bravely till the end.



*A barefoot health volunteer tracks Dasrath Singh's weight to check his recovery progress*

### **Dasrath Singh and wife Suraj Bai, Umraavan**

Dasrath Singh, aged 45, son of Kishore Singh, also worked in the same stone mine for almost 10 years and is also suffering from TB and suspected Silicosis. With the help of the BHVs, he recently came to be diagnosed with TB and has started undergoing the DOTS treatment. His wife is the ASHA worker and takes care of him and takes the main responsibility for the family income. Dasrath Singh continues to work in the stone mines on and off when they are hard up for money. Motivated by his father, he also takes herbal medicines, has given up alcohol and gutka and is, therefore, responding well to the DOTS treatment. Thanks to his wife who is an ASHA worker, who makes sure he regularly takes his medicines and visits the PHC, his condition is slowly improving.

### **Goni Bai, widow, Umraavan**

Goni Bai (age 40 years), lost her husband to TB (probably Silicosis too) a few years ago. She has been struggling to take care of her family of 4 children, all by herself since the last 8 years. Both she and her husband worked in the stone mines surrounding their village, which were mostly illegally operating. She has lost all her land for the PTR and was one of the few women, along with Janakabai, who fought to remain in the village despite the pressure of eviction. She went through a lot of struggle and anxiety while facing eviction as she found it stressful that as a single woman with four children, she was being forced to relocate to an unknown place and restart her life. The sense of insecurity and fear, along with her own ill-health took a toll on her. Yet, she was one of the most outspoken women who refused to leave her house



*Goni Bai*

and remained in the village, motivating other women to also stay back although the situation looked bleak, whether they relocated or stayed back. She struggled to deal with the crisis of electricity being disconnected by the officials and all other facilities like transport and job cards being withdrawn. She found it difficult to send her children to school outside the village as it was unsafe for them to go alone, both in terms of threats from the tiger as well as from non-tribals. She is dependent on NTFP like Mahua, Chironjee, Amla and daily wage labour. Seasonally, she migrates for harvesting work, to Chatarpur and other places in Panna. Having struggled all her life with the difficult work in the mines and survival after her husband's death, her health deteriorated. She has been complaining of body pain, cough, weakness and other symptoms of TB. Recently, the BHVs helped her get diagnosed at the PHC for TB and she is now undergoing the DOTS treatment. She has also started receiving the monthly Rs.500 under the programme for additional nutrition support. Since the treatment started, the BHVs motivated her to stop consuming tobacco. Now she sees a hope as her health has started improving and she aspires

to have a better opportunity to live once she is cured of TB. Watching her life transform has helped in motivating some of the men in the village who are also diagnosed with TB, to come out of their addictions. Two men in Umrahan have narrated their personal journey of stopping the consumption of substances like gutka and alcohol. This requires extreme determination, given the pain of the dual diseases, hunger and malnutrition.

### ***Surmila, Umrahan***

Surmila is barely 23 years old, married, with one child. Five years ago she was a healthy active girl who attended our women's group meetings and showed strong potential of becoming a young leader. Her life changed once she got married. Her husband and his parents are constantly demanding money from her widowed mother who struggles alone, working at odd construction sites to eke out a living. Surmila's father had worked in the mines for many years and succumbed to illness, possibly TB or Silicosis. Surmila is overburdened with housework as well as daily wage labour. Today, she is too frail and un-



*Surmila sitting outside her home in Umrahan with her child*

well. She demonstrates all symptoms of TB—is thin to the bone, with wracking cough and body pain, barely able to sit up from her cot. However, her family does not want to face the stigma of the illness and has declared that she is possessed by evil spirits and wanted to call a sorcerer. They refused to allow her to go to the hospital fearing medical ex-

penses and, when she became too ill to do any work, they sent her back to her mother's house in Umrahan. As Surmila was unable to perform any tasks, her husband abandoned her in her mother's house. Surmila is too unwell even to hold her child or feed him. Her mother is too poor to provide proper food or care. She survives only a single roti and some watery dal each day, which is all her mother can give. With difficulty, the BHV and ASHA worker had persuaded her to start the DOTS treatment and there was hope that with donations raised for her food and sustenance, she would survive the treatment. However, soon after she started the course, her husband returned and forcibly took her back to his village, as he needed an unpaid labourer for the harvesting work in the farm. Much as her mother pleaded that her daughter was in no condition to cope with any work, he took her away. At the time this report was being drafted, there is no information about Surmila and we can only hope that she survives the harvest, after which she will be abandoned in her mother's house again by her husband, and the BHV can motivate her to restart the DOTS treatment.



*Surmila struggles to keep her young child at a safe distance from her*

## **Section III Key Concerns**



## Findings from the Field

### Caregiving Falls on Women and Girls Heavy Workload on Caregiver Due to Having a Silicosis/Tuberculosis Patient in the Family

According to most of the respondents from all twelve villages we surveyed in Panna District, we found women as the primary caregivers in the family irrespective of their caste, age or number of family members or even, condition of their own health. For example Phulbahu, 80 years from Darera village takes care of Hiralal, a 60 years old son, a TB patient. These houses are also predominantly having either no other family members at present living to support the caregivers or they migrate for work. Geeta Bai, 38 years from Hirapur taking care of husband Chotu, 40 years for the last 3 years even when she herself is fighting TB for the last 12 years but now her 18 years old daughter-in-law Saraswati, who got married last year is helping her

even though she is pregnant herself. In some cases, even younger girl children like 13 year old Amrita, help to support adults/older male members who have no adult members in the family. These minor girls end up being the default caregivers, taking up small and big tasks including bringing the patients firewood, water, cooking, washing or sometimes being the only ones accompanying the adult to the hospital.

In multiple cases, caregivers are also the sole breadwinners of the family and hence they face the double brunt of household work and going out for wage labour, irrespective of their own health condition. For the women, even these household tasks have be-



*A young girl buys milk for her TB-diagnosed aunt in Umrvan village, Panna*



*An elderly caregiver collecting firewood near Umrahan*

come much more strenuous and hazardous as the PTR restrictions and increase in tiger population pose physical risks, longer hours of walking far to fetch firewood and other resources, while also facing the harassment of forest guards. Where the families submitted to relocation, their condition is worse as access to forest for food, incomes or utility items has come under severe stress. Their original source of wild food that provided some nutrition and herbal remedies are no longer available.

The most glaring factor in each household was the lack of food. Such severe distress in access to food exists in not a few, but in almost all households. Single roti with watery dal or single meals per day are a regular feature in these villages. To expect these families to overcome tuberculosis even when going through the DOTS medication is far fetched. Women, whether caregivers or patients, deny themselves proper food in order to feed their families. Hence, the recovery of women suffering from TB or Silicosis makes it all the more harder.

## Financial and Psychological Stress on Caregivers

In almost all the cases, Silicosis/Tuberculosis worsened the financial situation of the family. Most of the patients were earning members of the family, so the immediate

impact of loss of incomes led to women or adolescent children taking over the primary role of earning. In most of the families interviewed, either they depended on the wife's



wages or children dropped out of school to work in construction or farm labour. Women reported that they had to sell their cattle and jewelry for medical expenses or pay high interest on the collateral for the jewelry. During all these processes of arranging money to go around hospitals with patients, the women shared the mental and psychological stress they undergo in their desperation to save their loved ones.

One of other major factors is uncertainties in work opportunities. Irregular wages caused difficulties in coping with medical expenses leading to severe debt that directly affected the family's food intake. All the participants reported not being able to give proper nutrition to the patients while the caregivers often went hungry to feed the rest of the family. They mainly depend on the ration from the PDS which is insufficient, and many do not possess ration cards after relocation. One of the major causes of relapse in TB

despite taking multiple cycles of the DOTS course, seems to be the poor nutrition coupled with heavy work loads and it feels like a cruel irony when doctors tell them that good nutrition is a must for them to get well.

When the breadwinner is the patient, the patient is also the breadwinner and caregiver, particularly with respect to women, the struggle for survival during the illness makes it difficult for them to come out of the illness despite repeated doses. Majority of the patients interviewed, including women, had developed resistance to the TB drugs and did not know the seriousness of completing the course, nor had the opportunity to have a stable access to public health care during their illness, with the constant pressures of migration and relocation. Care and support post the DOTS course is also completely absent, thereby making patients slip into cycles of TB and malnutrition.

## Caregivers' Own Physical and Mental Health - A Serious Concern

In terms of physical health of women caregivers, headache, bodyache, tiredness, back pain, fever, irritation and getting angry easily are one of the common symptoms they shared. Almost all of them mentioned irregularities in menstrual cycles, from 2-4 months and stomach ache/ back pain, white discharge etc during that time. One or two of the respondents showed visible physical signs like swelling of body parts and very itchy abscesses on the body.

Another common tendency they mentioned is that until or unless they are really sick, in their own language – bedridden, then only they go to a doctor for medicine or take rest. Otherwise women take local herbal medicines recommended by some elders in the village. During their sickness, they cannot afford to take a special diet other than Chapa-

ti or Rice with very watery dal. They also mentioned about getting anxious and unable to cope with the care-giving work when they are sick. They are also worried about the work burden passing on to their young daughters during their sickness and most of them mentioned daughters as their main pillars of support when they are sick.

Multiple women also mentioned consuming gutka and tobacco as their way out to cope with the physical pain and mental stress. We found that this crisis has been normalised in the community so much that, to make a difference between the ill and the not so ill, is difficult. They all live as if TB and Silicosis are a common cold and cough that disappear after a small dose of alcohol.

When it comes to mental health, almost all



*A typical afternoon meal of rice and watery dal at a TB patient's home*

of them are mentally tense about their family's health and financial situation, especially the pressure they face from money lenders. They mentioned being physically and mentally exhausted and a sense of hopelessness about the situation at home. These women are also worried and anxious when family members are not finding work or not able to buy food due to inflation in prices. None complained too much about care work as a burden. As one woman put it, 'even a day is less for the amount of work I am supposed to finish'. Getting support from extended family and neighbours in terms of food or money was mixed since some mentioned getting support while others were not so lucky as almost all the Gond families are in a similar situation.

Almost all the families interviewed having TB/Silicosis resulted in children dropping out of school, particularly teenage children. Boys are forced to take over the mine or construction labour work, and many families reported a second and third generation TB/Silicosis patient among these young men. Almost all

of them interviewed have got addicted to at least one substance. Girls have dropped out to take over the household chores and also to migrate with their families for work.



***The two diseases have brought a vicious web of the same diseases on to multiple generations. For the women, especially young widows, this is the hardest emotional struggle to cope with.***



## Dependence on Substances High - Workers Blamed for the Illness

The study found widespread consumption of alcohol and usage of Tobacco and Gutka in the affected villages. Nearly half of them (47 %) reported occasional or heavy use of all 3 substances. The real number is likely to be higher due to reluctance on the part of respondents to respond. Up to 60 % reported the use of 2 or more substances and 89% reported the use of at least 1 substance. There is anecdotal and observational evidence of even children as young as 10 years old consuming Gutka. Respondents reveal that without these substances they find it extremely difficult to withstand the pain of the disease and the complications from the medicines taken for TB. The impact of these addictions are directly on women's health and security. Domestic violence, alcoholism and constant abuse by ailing men brings upon women the weight of enduring the violence, the guilt and despair of trying to justify the bitterness of the patients and the sense of helplessness of having to continue in this situation with all the multiple pressures. Some of the women

also resort to alcohol as their only means of coping with the stress and hunger. They often hear condescending remarks from local authorities and health personnel, blaming their addictions for the illnesses, rather than understanding their context of hazardous labour and cycles of poverty. Hence, often, women refrain from taking advice or seeking help, as was seen in Panna. Compounded by this is their lack of hope that relief can be expected from the system or from the outside, especially as they have witnessed generation after generation caught in this Silicosis web. Some of the women who also suffer from TB in these study sites, refused to undergo diagnosis or treatment as they neither have the energy nor resources nor hope that they can sustain through the DOTS course. It was this despair that was most glaring during our conversations with the women and we found that peer support through our barefoot health programme is what is helping them slowly, in gaining a sense of hope.

## Mine Workers Face Several Legal and Human Rights Violations

All of the respondents said that they worked in stone mines located both near and far from their village. Most of them began working in the mines between the ages of 12 to 16. **The median age at which they start working in the mines is 15 years.** The majority of the mine workers surveyed (up to 90%) were men but there were some women too who have worked in the mines for a long time. This is due to the fact that it is primarily men from these villages who go to work at the mines while the women gather NTFP, work as construction or agricultural laborers or do unpaid work at home and at family farms.

All the men reported that they worked as stone cutters exposing them to more dust and stone particles while the women primarily worked in loading and stone breaking and they also come in contact with dust and stone particles during work and while washing clothes.

**The median number of years worked in the mine for all the respondents is 20 years.** But there are many individuals who worked there their whole lives up to 30 or even 40 years. This fact becomes relevant when we look at the severity of Tuberculosis and suspected



*Workers at a stone mine near Panna*

Silicosis cases. A clear correlation emerges between the number of years worked in the mine and the severity of the cases.

Out of the total number of households surveyed, half of them, 50%, have at least one individual who has been officially diagnosed with Tuberculosis. When you add the cases of suspected or confirmed Silicosis to the number of tuberculosis patients the percentage goes up to **71% of total respondents**. Of these, **66% of them have worked in the stone mines for more than 20 years**. **47% of surveyed households have at least 1 family member who is seasonally migrating for work**. Out of these 27 respondents who were individually interviewed, the vast majority of them, 24, characterize their illness as moderate or severe.

It is also suspected that most of the cases in these villages diagnosed as Tuberculosis (TB) could be **Silicosis or Silicotuberculosis**,

**and is either accidentally or deliberately being misdiagnosed as TB, while Silicosis treatment or even symptomatic care is completely absent except for prescribing painkillers or cough syrups. Out of all the TB patients surveyed 73 % of them have been sick for 5 years or more.** Some of them have been sick for more than 15 or 20 years. Many of them have reported that they have undergone multiple rounds of treatment for Tuberculosis and still haven't recovered after many years, revealing the resistance developed to the DOTS course or the medical negligence in treating for Silicosis.

From testimonies of workers it is evident that most of the mines were illegally operating or were unregulated as workers did not know who the owners of the mines were, did not get any identity cards or safety equipment, and had to often shift from one mine to another. Often, they were caught and fined by the forest guards while digging, whereas

the contractors escaped punitive actions. All respondents reported that there was **no safety equipment given to them while they were working at the mine, whether it had a licence or not.** None of them have had any labour cards or are registered employees of any company, and hence have no proof to submit that they were mine workers at particular mines. They were working in mines locally as well as in other states, making it even more difficult for them to seek medical treatment or state rehabilitation. The health condition of these workers demonstrates that operational costs of the mining industry are highly compromised with regard to labour and environment standards and statutes.



*The huge losses incurred by these workers and their families -financially, physically, emotionally and intergenerationally in multiple other forms, is not accounted for in the cost-benefit analysis or in the economics of valuation of minerals and their production costs.*



## Access to Government Schemes and Services - Negligent

One of the major findings of the study is that **only 28% of households reported that they go to government hospitals** in the event of a serious illness such as TB or Silicosis. The rest of them travel to private hospitals in towns such as Nawagaon, Chattarpur or Satna which are 100 to 150 km in distance compared to the government hospital in Panna which is only 13 to 15 km away from their villages. This is due to the fact that the nearby government hospitals are ill equipped to treat serious illnesses and until recently, did not have the necessary equipment or the interest to diagnose Silicosis. The longer travel distance also creates more financial and psychological burden on the patients and their families. Recently, after Covid, the PHC in Panna seems to have upgraded its Silicosis testing facilities, and for the first time, patients received health cards diagnosing them as Silicosis positive. However, there are no other facilities for care and support at the PHC or for community follow-up to rehabil-

itate the Silicosis afflicted. This leaves the patients with simply an acknowledgement of the disease in the absence of any rehabilitation policy or budgets.

Treatment at private hospitals also ends up costing more and adds to the overall medical expenses over time. **47% of households reported medical expenses exceeding Rs. 50,000** over the course of a few years compared to the median of Rs. 30,000. Almost all of these households reported going to private doctors or hospitals. This is again connected to the amount of loans these households have taken to cover these medical expenses. More than 42% of the total households surveyed have loans above the median of Rs.30000, ranging all the way up to 4 lakhs. All of these loans are again from either neighbors, relatives or private micro finance companies who charge exorbitant interest rates. Most of the relocated families exhausted the money received as compensa-

tion, for medical expenses, travel and debts incurred for basic sustenance during illnesses. Hence the NTEP's integrated approaches of Differentiated TB Care for patients with comorbidities and risks, the implementation of the "Pradhan Mantri TB Mukht Bharat Abhiyaan (PMTBMBA)", Ayushman Bharat and other schemes rolled out for the eradication of TB and to achieve zero catastrophic costs to patients, does not appear to have reached these poor Gond families in Panna who continue to be weighed down by expenditures and debts beyond their means.

None of the households surveyed have any health insurance and have never used the Ayushman health card.

None of the families have reported receiving any supplementary nutrition or any other type of support from the government apart from PDS and a pension of Rs. 500, both of which many claim they did not receive due to complications in their identity cards after relocation. It was quite evident from the poverty and ill-health in these families, that even the Rs.500 barely made a difference to improving the health of the patients or their



*ASHA workers visit them under whose observation and supervision the DOT treatment for TB is supposed to be taken. But the ASHA workers themselves are very poor, receive very poor remuneration, lack information and training, and suffer from Silicosis and TB within their own families, which leaves them little time for community work, when they are busy being caregivers at home.*



*Our team assisted relocated families in applying for the transfer of their documents like Aadhaar card, which would help them access schemes*



*Our bare-foot health volunteer handing over medicines and nutrition supplements to a TB patient in Madaiyan village*

families, considering the recurrence of the illness and repeated courses they took and have become drug resistant to.

Participants responded in the negative to the mention of the various schemes available to them, citing a lack of awareness of the scheme or them being ineligible for various reasons like not having Aadhar card, caste certificates, ration cards. The ordeal of trying to get these documents forces them to give up. Even though Swachh Bharat toilets were constructed in some houses, none of them were functional.



***There is almost no house that has a functional toilet in the study villages and open defecation especially among Adivasi households is universal. Lack of toilet facilities in such conditions as TB and Silicosis where the patient is barely able to breathe or sit up, poses extreme hardship for the patient as well as to the caregiver.***



Women have to carry the men outside into the forest when they themselves are very frail and unwell or spend extra hours cleaning up the house when men defecate inside. In villages like Umrahan and Kaimasan, people face a high risk of confronting tigers when they go out for toilet needs and for the women, it is a constant worry carrying the men with them.



***Only 31% of total households said that they have Ayushman Cards but none of them were able to use them.***



This is the case for many other schemes and services where there is either a lack of awareness on how to apply for them or the



*Our team assists patients to get their timely check-ups like blood tests and scans at the PHC*

relocation for the PTR left them with huge gaps in getting these entitlements in their new colonies, even after 15 years of relocation. Coming to compensation and pension schemes, only 4 households said that they received the Rs.500 pension for six months after the TB diagnosis and none for Silicosis as the Madhya Pradesh government does not, till date, have a Silicosis prevention or rehabilitation policy.

The data also shows multiple challenges in the delivery of public health facilities. Unless patients approach the PHC, there are no proactive community intervention drives to identify and motivate people suffering from these illnesses. Procedures like sputum collection at the village are slow and erratic, that leaves huge gaps in the patient undergoing the course uninterrupted. Often, for lack of money to take the bus, or the long walk to the PHC, we found people had dropped out of the DOTS course. Mere clinical intervention of TB seems ineffective and it is alarming how most of the patients have developed MDR and continue to suffer. TB prevalence persists and the present forms of treatment are medically, economically and administratively inadequate. While there is an ambitious objective of bringing about a 'TB Free Tribal India', the Ashwasan programme has

**not even identified some of these high prevalence areas.** In M.P, Panna and Vidisha districts where concentrated populations of STs and SCs with high prevalence of TB continue to suffer, they have been missed out of the Ashwasan list of districts.



***A more serious mapping of tribal areas and tribal populations is needed to plan extensive coverage under the National Tuberculosis Mission and Silicosis Prevention.***



At the health infrastructure level, some improvement is visible in Panna PHC with regard to equipment being installed for diagnosis of Silicosis. Our recent experience with the



barefoot health programme gave a positive result as the medical personnel were cooperative in diagnosing the illness, and providing medical support to patients of TB. It was a demonstration of **good collaboration when local NGOs receive positive responses to patients referred by them in a public hospital. Within a short period, medical intervention by the PHC and community follow-up by barefoot health volunteers, together brought some medical relief to patients.** However, in the absence of this collaboration, patients neglect getting diagnosed or going for treatment, given their multiple hur-

dles of poverty and lack of confidence in accessing public health care. The public health structure is ill-equipped to reach out to the poor communities on its own, obstructed on several fronts of human resource shortages, poor budgets, lack of transport facilities or political and administrative support. **Delivery of healthcare depends on the goodwill of individual doctors. It is only during the Covid pandemic that a few efforts to upgrade PHC infrastructure helped** in at least, clinically providing a diagnosis section for Silicosis, in the PHC. Till date, even this acknowledgment was absent.

## Caregivers Suffer When Social Security Schemes are Poor: Link Between Health and Other Development Indicators

In the study villages, daily struggles for existence have been exacerbated both in relocated colonies and also where families did not choose to relocate. In the new sites (after 15 years), women have a harder time collecting water as very few amenities have been created in these colonies. Their stress over health problems at home is compounded by the daily battles with neighbouring non-tribal villages where they walk to fetch water. Women have lost access to firewood and fodder as they had no choice but to relocate to highly degraded places. Life has become tougher in their daily chores of cooking and they are considered criminals if they discreetly collect firewood. In villages like Umrahan and

Kaimasan, women face many restrictions to enter the forest, and hence firewood collection is fraught with fear of the tigers and the forest guards. The women have given up collecting fodder as they have stopped purchasing livestock after most of their cattle died from wildlife attacks. This resulted in women's direct income and nutrition losses. Only a few families have received LPG cylinders for cooking but they are of no use when they don't have the money for the refill. The table below shows how ineffective this facility has been and the time spent both on caregiving and firewood collection has only multiplied women's unpaid workload in Panna.

**Table 9: LPG access and constraints for women**

Sno	Village, Panchayat	Total HH	HHs with LPG connection 2018-2021	Tribal HH	Non Tribal HH	Refill in a year	Reasons for non utilisation
1	Kaimasan, Bador	82	15	12	3	2 families - 2 times	

Sno	Village, Panchayat	Total HH	HHs with LPG connection 2018-2021	Tribal HH	Non Tribal HH	Refill in a year	Reasons for non utilisation
2	Bador, Bador	217	28	8	20	4 families - 3 times	1. High price of LPG refill
						3 families - 3 times	2. Firewood has no expense
						1 family - 1 time	3. Family poverty
						1 family - 2 times	4. Ignorance and fear of using LPG
5. Transportation cost is high							
3	Hirapur, Sakariya	75	52	50	2	2 families - 2 times (upper caste)	1. High price of LPG
							2. Fears over safety
							3. No transport.
4	Darera, Manor	138	35	12	23	5 families - 2 times	1. High price of LPG
							2. Firewood easier to collect
							3. Cannot afford
							4. Lack awareness on usage
							5. Fear of using LPG
5	Madaiya, Bador	57	32	30	2	1-2 times	1. Cannot afford, high price of LPG
							2. Firewood easier to collect
							3. Fear & lack of awareness on usage
							4. High transportation cost
6	Umraavan, Bador	13	9	9	0	2 families - 1 to 2 times	1. Cannot afford
							2. Firewood easier to collect with no cost

The table above details LPG connections among the ST households and reasons for low rates of LPG usage. This table is provided to indicate how social security schemes

for ST women are inaccessible when they are confronted with multiple hurdles like inability to afford LPG as an energy source for cooking, lack of transport facilities in these

remote areas, thereby increasing the cost of refilling and the additional burden on women in going longer distances for firewood when they face restrictions in forest usage. The problem of having TB and Silicosis causes

greater physical suffering to the victims due to toxic gases from cheaper qualities of firewood they have to depend on today, thereby aggravating the health crisis in addition to additional work loads and safety concerns.



*A woman cooking on a firewood stove*

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## **Relocation Without Proper Rehabilitation - Doomed If You Leave, Damned If You Stay Lack of Access to Remedies**

All families interviewed complained that their suffering increased after displacement, whether they remained in their native villages or relocated to new sites. Both options of the resettlement package - whether they chose monetary compensation or non-monetary resettlement, they ended up being cheated and abandoned due to numerous lapses in getting fair and complete rehabilitation. Almost all the relocated colonies complained that it took them years to get access to PDS

in the new sites, and still do not have proper anganwadi or school or road facilities. Most relocated colonies do not have proof of purchase of land from non-tribals, and in most cases, a lot of these small parcels of housing sites have been further encroached by outsiders with local administration paying a deaf ear to their several applications for redress. In sites where the forest department relocated them with land as compensation, they reported that these lands are uncultivable and

without proper pattas. It was found that in some of the sites, families have abandoned these lands and are untraceable. In almost all relocated colonies, fraudulent insurance companies and banks grabbed their money and are untraceable.

In the villages where families chose to stay back, basic entitlements are elusive due to restrictions of PTR, whether with respect to roads, electricity, drinking water or MGNREGA, thereby leading to economic distress and ill health. Their existence is ambiguous as families are shuffled on paper to other pan-chayats through voters' lists or PDS ration.



*The distress of poverty and migration after relocation result in an accelerated risk of malnutrition, TB and other occupational illnesses like Silicosis which we saw in all the relocated sites.*



*They live life as if their citizenship has been suspended where many do not know which village they now belong to, nor do they have ration cards.*



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Name : BHANGUTI BAI  
 G. Name : [Redacted]  
 Address : [Redacted]  
 TEH-PANNA DIST-  
 PANNA  
 SUB-REGISTRATION LETTER

Branch : KATNI  
 Address : 2 nd Floor, above VK Motors, Bhatta Mohalla, Jabalpur road, KATNI-

Dear Sir/Madam,  
 In response to your application, we are pleased to inform you that you have been registered for the Land booked by you as per details furnished hereunder. The terms of booking and allotment shall be governed by the terms of agreement and general terms of conditions printed overleaf.

Registration No. & Date of Commencement	Plan No. & Term	Consideration Land Size (Sq. Feet)	Mode of Payment	No. of Installments	Installment Amount (Rs.)
30-09-2010	Plan- C1 6Y 0M	200	Single	1	Rs. 10,000.00
First Receipt No. and Date	Next Due Date	Last Date of Payment	Expiry Date of Agreement	Expected cost of Plot on Expiry of Agreement	
30-09-2010		30-09-2010	30-09-2016	Rs. 20,000.00	
Applicant's Age	55Yrs.	Nominee's Name Age & Relation	LAKHAN SINGH 29Yrs. Nephew		
MIS Details		Agency Code	029000181		
Amount in Words (Expected cost of Land on Expiry of Agreement)	Rs. Twenty Thousands And Paise Zero Only				

**CASH DOWN PAYMENT/FIRST INSTALLMENT/ RECEIPT-CUM-ACCEPTANCE LETTER**

Received with thanks from the undermentioned Customer the amount of cash down payment/First Installment of Installment Payment Plan alongwith application fee of Rs. 10/- for acquisition of Land (s).

Customer's Name, Age & Address :  
 Name : BHANGUTI BAI  
 G. Name : [Redacted]  
 Address : [Redacted]

Nominee : LAKHAN SINGH  
 Age : 29 Yrs. Relation : Nephew

Registration No : [Redacted]  
 Date of Comm. : 30-09-2010  
 Plan Term : Plan- C1 6Y 0M  
 Consideration Rs. : 10,000.00  
 Amt. Of First Inst. Rs. : 10,000.00  
 Next Due Date : [Redacted]  
 Expiry Date : 30-09-2016  
 Agency Code : 009000187/029000181

Amount in Words :

*The receipt of a land registration. Bhanguti Bai never got her land even though she paid the amount.*



*A rocky and unlevelled plot of land received by a family after relocation*

## Impact of Tuberculosis and Silicosis on Children

Often after their father or mother passes away from Tuberculosis or Silicosis, children are pulled out of school to help with the family's sustenance and to pay up the debts. We found boys as young as 11 and 12 facing the pressure of becoming breadwinners of their families and girls dropping out to help their ailing mothers with household chores. There is a crisis after primary level, and by class 7 and 8, we found most children of these families out of school and migrating for work, even if they are technically enrolled in school.

Children's enrolment in schools has been challenging as government schools refuse to admit them without the supporting documents of caste certificates and Aadhar cards. Given their financial condition, families have not been able to run around to get these documents in their daily struggle for survival after relocation, and **the distress of poverty leading to child labour, resulted in many of**



***Secondary data for Panna district shows a high rate of enrolment in school for ST children, but the ground realities reveal that they are actually not in school for most part of the year.***



the relocated families to stop sending their children to school, especially among the more vulnerable Nand Gond and Sor Gond families. Even the monetary compensation for some families is pending. When district administration does not step in from all departments concerned - whether revenue, women and child welfare, health or education - to extend services to relocated sites, the displaced families appear to be forgotten once the eviction is done.

Other reasons for drop-outs are relocation to sites that have no schools or transport facilities or not having the required documents despite the RTE Act providing for compulsory and universal education especially for vulnerable children. Additionally, those living near the PTR find it very risky to walk through the forest as people report that the number of tigers and leopards has increased.



*Both displacement and Silicosis have forced children to take over the responsibilities of wage labour. For children not attending school, the one assured mid-day meal that they get in school is also a distant dream.*



*A child in Bador helping his mother in the kitchen. He could not get enrolled in school as he does not have an Aadhaar card.*

Having a patient with TB increases the childrens' chances of contracting the infection and when they do, the symptoms are rather severe and the potency of the medicine gives a lot of pain and discomfort. **Especially the Sor Gond and Nand Gond children are suffering from chronic ill health and lack of proper nutrition that also impacts their learning and retention skills. Many children, under the influence of their peers, start using substances like Beedi or gutkha or alcohol to numb their pain.** One child said that they started consuming these substances at a very young age since they saw their parents, siblings and friends consume them. Another girl child said, "my big sister gave it to us for the first time and then we got used to it". The children themselves, particularly from the very poor Sor Gond families, have little motivation to go to school and the parents are too preoccupied with migration and ill health, to focus on education.

**It is a challenge for even motivated government school teachers or local NGOs to find ways of addressing the migration related constraints.** There is no sustained state intervention on the ground either to provide

local livelihoods that can reduce the migration itself (with MGNREGA barely reaching the Gonds in these villages and unlikely to do so in the reduced union budget allocations) or create residential education opportunities for children of migrant workers so that parents can be persuaded to retain their children in school. It is particularly worrying that in areas like Panna where restrictions of Protected Areas over creating roads, transport and other facilities for local communities create hurdles for their education, alternate ways of addressing the community needs, especially that of children, have not been put into place. Children are regularly migrating with their families and live in unhygienic and insanitary conditions and with very poor nutrition in migration sites and are exposed to infections when their adults suffer from TB and Silicosis. Therefore, they have borne a severe price of poor rehabilitation, whether of education or of protection from communicable illnesses like TB and addictive substances. The personal stories shared by the community also indicate that for girls, (and boys), migration and lack of transport to school have increased their vulnerability to sexual abuse.

**Table 10 - Children out of school in the study sites**

Village	No of Children Out of School*	Tribe	Age groups	Classes	Reasons for Being Out of School
Hirapur	54	Gond	06-14	01-10	1. Way to school is lacking security and a mode of transport.
					2. Most children have no official identification documents like birth certificates and Aadhar cards.
Darera	17	Gond	06-14	01-10	1. Enrolled but unable to go to school regularly.
					2. Caregiving responsibilities keep them out of school

Village	No of Children Out of School*	Tribe	Age groups	Classes	Reasons for Being Out of School
Bador	16	Gond	06-14	01-10	1. Enrolled but unable to go to school regularly.
					2. Caregiving responsibilities keep them out of school
					3. No identification documents like Aadhar card
Madaiya	8	Gond	06-14	01-10	Same as above, other unspecified reasons
Umravan	4	Gond	06-14	01-10	Migration
Kaimasan	2	Gond	06-14	01-10	Same as above, other unspecified reasons

(\*Not Attending School is interpreted as children who have either dropped out of school completely or may be enrolled in school but are absent for prolonged periods due to migration and other factors.)

National Family Health Survey 2015-16 stands as testimony to the poor health condition of tribal children in M.P as is visible in Panna. It finds that IMR for tribes stood at 58.9, highest among all social groups and estimates of under five mortality (78.5) are also exceedingly high. Therefore NFHS states that 'exceptionally large numbers of tribal children in Madhya Pradesh remain devoid

of the basic services and facilities available to other children of their age.' Further in non-scheduled pockets like Panna with complex problems like illegal mining and relocation for development projects, the vulnerability to malnutrition and TB among children has higher potential and this was observed in all the villages studied.

## Mine Area Rehabilitation from Special Purpose Funds: Invisibility of DMFT

Almost all the families covered in this study are mining affected and eligible for not only rehabilitation and compensation from the Ministry of Labour for Silicosis and occupational health problems, but also from the District Mineral Funds. These special purpose funds under the PMKKKY are to be utilised in all mining affected districts for the rehabilitation of mining affected communities and restoration of their eco-systems and livelihoods. Yet in Panna (or for that matter, Mad-

hya Pradesh), there is no information about the expenditures under the District Mineral Funds available in the public domain. As stipulated by the ministry, there are no online or offline reports of DMF annual plans or expenditures for Madhya Pradesh in the public domain, leave alone the stipulated five year plans under the PMKKKY. None of the villages covered in the study heard of the DMF funds, and we could not avail of information from the district offices. It is only from hear-



say that we have been told of the PHC being upgraded and infrastructure for schools, but whether these are from the DMF or from the Covid medical funds is unclear. While Panna is India's pride of being the country's diamond producing district, STs in Panna affected by the diamond and stone mines remain utterly poor and suffering from both TB and Silicosis. There have been several applications from local communities to the district authorities for employment guarantee locally, and **the DMF could be utilised for MGNREGA, health extension support, rehabilitation of resettled villages, Silicosis pensions and other social security support for TB and Silicosis affected families. Rather, these families should be the first to be entitled for use of these funds.**

The DMFT funds for vigilance and regulation with regard to illegal mining is also not discernable while the prevalence of Silicosis is strongly indicative of the presence of mining operations. The DMF resources need to be urgently utilised for regulation of illegal mines and reclamation of mine pits and workers. **Although small patches of Southern Panna were taken for tree plantation under the Green India Mission (GIM) financed by the World Bank in abandoned mine sites, it is baffling why external funds were required when the DMF funds are accrued annually.** However, there is no information available on fund utilisation.



***The DMFT has women and children as a high priority category. Yet in Panna, we do not have information on benefit flows from DMF to these directly affected Gond women and children.***





## **Recommendations and Conclusion**

## Need for an Intersectional and Multidisciplinary Approach to Addressing Silicotuberculosis

As the AIGGPA road map for Madhya Pradesh states, ‘there is a tendency among the planners and administrators to investigate malnutrition as a health-related issue, and accordingly the interventions also focus on the same. However, factors such as livelihood practices and poverty are often missed out on. The evidence above necessitates that the problem of malnutrition should be dealt with in a more comprehensive and multi-disciplinary approach as ill-health among the Gonds in Panna is linked to their resource access, marginalisation on all development interventions, economic distress and relocation. The DOTS programme being ineffective needs to be reviewed from all these aspects, especially in the context of women and children in Panna.



***The TB Free Tribal India initiative could be clubbed with the DMF funds for these pockets which are neither covered under the Ashwasan programme nor the DMF.***



## Comprehensive Health Support in Multiple Decentralised Systems for Tribal Areas

The public health systems and human resources have been screeching for attention, particularly, the public health system for tribal areas in M.P, despite highly articulate expert groups raising concerns. There is a stated commitment as far as TB eradication is concerned where the India TB Report of 2023 states, “the NTEP has been unwavering in curtailing the impediments in managing DR-TB patients. To offer the last-mile service delivery for better access and quality care to TB patients, including DR-TB patients and their close contacts, the programme has decentralized TB services to the Ayushman Bharat – Health and Wellness Centres”. However, on the ground, the upgradation is not evident on multiple fronts. Most expenses

seem to be more focussed on adding infrastructure and not bringing qualified medical teams, specialists, medical equipment, and investments in community outreach. Considering the high odds among these families to continue with the treatment till the end, public health systems need to improve their human resources at community levels in order to ensure effective identification, motivation and follow up protocols.

There have been several recommendations like reorganisation of the service delivery mechanisms in tribal areas through training tribal ASHAs; recruiting and training motivated Tribal Health Volunteers at village level; setting up of hamlet level VHSNCs; setting



*TB patients from Kaimasan travel to the PHC in an autorickshaw*

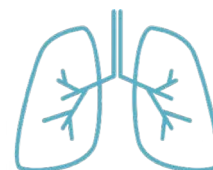
up of Tribal Health and Wellness Centres at the community level (with a population coverage of 3000) in pockets of over 50% tribal population; mobile outreach services in difficult to access regions that are far from PHCs, setting up of additional PHCs and sub centres, specialist doctors to be appointed in tribal areas and other medical and social resources. Although the report on HWCs by the Ministry of Health and Family Welfare indicates that these systems are in place, the actual functioning is far from accessible to the last mile patients and caregivers in tribal areas. The current training and remuneration for ASHA workers is not adequate enough to motivate them in the discharge of their responsibilities. Sputum collection facilities, facilities for symptomatic care of Silicosis patients at community level, travel allowance for PHC visits for check-up for patients and caregivers, post treatment care and support to prevent relapse and provide lifelong palliative care for Silicosis affected are some of the public health support measures for responsible governance.

Some recommendations (Nandini Sharma et al 2016) that are specifically advocated for Silicosis prevention and care, apart from a demand for integrating the Silicosis with the

national tuberculosis prevention programme are, “an occupational health and dust survey along with clinical examination, chest radiography and pulmonary function tests of workers every six months should be made mandatory in potentially hazardous industries. Cost-effective engineering control measures to manage silica dust need to be developed and promoted.



***Silicosis is a notified disease under the Mines Act (1952) and the Factories Act (1948). It should also be made a notifiable disease under the Public Health Act, so that reporting becomes mandatory.***



Awareness campaigns are needed to sensitize workers about their risk of Silicosis, personal protective measures and early symptoms.” Further, there is an ethical and medical concern where sensitivity to workers’ health, particularly in relation to Silicosis is not taken into account while treating patients with Tuberculosis, that compromises the risk and suffering of Silicosis patients.

Therefore, it is recommended that, “Occupational history-taking must be mandatory to differentiate Silicosis from pulmonary tuberculosis and hence avoid the risk of unnecessary anti-tubercular therapy for the former. In areas with Silicosis-risk industries the sputum of suspected cases of tuberculosis should be cultured and given antibiotic susceptibility testing.”

## Silicosis and Silico-Tuberculosis Prevention and Rehabilitation Policy for Madhya Pradesh Urgently Needs to be Passed

Madhya Pradesh has still not formulated a policy for prevention and rehabilitation with regard to Silicosis. Despite the NHRC directives, diagnosis and rehabilitation are nearly absent.

The state needs to allocate clear and adequate budgets and set up structures that can identify, diagnose and make rehabilitation accessible to tribals (and other workers) with immediate effect, as death is a common occurrence with its related burdens on the surviving women and children.



***Urgent need for the state policy and guidelines on occupational health and safety rules for the treatment and long term support to families affected by Silicosis, is a necessary state obligation.***



## Convergence and Regulation

Regulation of mine and other industrial sites, reviewing the standards and protocols in dust management, interdepartmental linkages like mandatory reporting of Silicosis diagnosed by PHCs to labour departments and the latter’s collaboration with the health department in reviewing the periodic medical testing by industries should be made mandatory procedures in the regulation of mines and other industries. The onus of immediate action for identification, diagnosis and rehabilitation should vest with the la-

bour department, irrespective of the source of contracting the disease and proof of employment. Patient verification and registration for convergence with other departmental interventions are urgently required where compensation, pensions, funeral expenses, education and nutrition support and other rehabilitation schemes should automatically be digitally registered (particularly as the national government has committed to digitisation in a large scale) so that affected families are not left to run from one department to

the other, trying to avail of these benefits as these families are too poor to afford costs of documentation, travel and other expenses or the capacity to survive through the delays in implementation. There should be a strict time period defined in the rehabilitation pol-

icies which include a penalty to be paid by the department to the victims and their families for delays in reimbursements, payment after death of workers in order to strengthen accountability and humanitarian outreach from state institutions.



*A stone mine in Panna*

## Transparency and Effective Implementation of DMF for TB and Silicosis for Mining Affected - An Urgent Requirement

Current implementation of DMF funds are haphazard, ad hoc and mostly, do not address the direct impacts of mineral operations on workers, communities and habitats. Therefore, proper assessment of mining areas and formal consultation with the affected populations through due diligence consti-

tutional procedures is urgently required for implementation of the DMFT. **The Madhya Pradesh government should respect the PMKKKY guidelines and disclose regular information on annual plans, expenditures and five year plans in the public domain for each district.**



*The DMF five year plans and expenditures should clearly include allocations for eradication of these two diseases with funds for immediate relief and rehabilitation and long term care.*



Prevention of migration and disease by creating sustainable local livelihoods through DMF funds are a responsibility of the state authorities.

Further, the annual plans and five year plans should include adequate rehabilitation, caregiver pensions, nutrition support and welfare schemes for caregivers with the DMF funds that will provide them with dignity of physical and psychological rehabilitation. **Women as caregivers need to be provided pensions for their unpaid caregiving work** as their situation leaves them with lesser time to seek paid work and suffer from lack of resources for nutrition. On the other hand, even the Rs. 500 for additional nutrition of TB patients is difficult to access for these relocated communities.



*A comprehensive and adequate nutrition and social security support intervention programme has to be specifically created for Caregivers and women and children of Silicosis- Tuberculosis patients. There are adequate funds under the DMF for such directly affected people.*

*The TB-Free Tribal India programme, National Health Mission's palliative care programme, cleaning up of water bodies contaminated and depleted by mineral operations should be extended to these non-scheduled areas by tapping into the DMF resources.*



*A TB patient from Madaiyan with his medicines*

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## Illegal Mining - Urgency to Curb and Regulate

Almost all the patients with Silicosis and majority of TB affected from the study area were reported by the workers to be working in or having worked in informal and unlicensed mines where workers have no information or the power to seek information about the mining license, mine owner, lease period of the mine or such other legal details. Therefore, none of them have been registered under the Shramik portal. Nor do workers have the power to demand for job registration, work safety equipment, decent wages or compensation and rehabilitation for accidents, injuries or ill health caused by mining. Distress migration forces these communities to shift between local and interstate mines or other labour activities with no proof of their work status other than their lungs. Yet, state mechanisms demand workers who file for compensation, to produce evidence of their employment in the mines.



*Irrespective of the victims having proof of employment, the Silicosis affected have to be immediately rehabilitated with a comprehensive time-bound implementation. Punitive action on the relevant authorities in the discharge of rehabilitation actions have to be taken in order to effectuate speedy and humanitarian action to save lives and suffering.*



## Identifying and Mapping TB and Silicosis Pockets for Tribal Areas to Have More Rigour and Priority

Identification of TB affected areas needs review-particularly ST populations outside the Scheduled Areas have been left out. There is no mention of Silicosis even in the special health problems in the AIGGPA report which lays down the roadmap for health intervention and planning for Madhya Pradesh, reflecting that this critical health problem has been ignored entirely. Districts like Panna, Vidisha and other tribal pockets that are outside the Scheduled Areas are more neglected despite having high tribal populations, including PVTGs. Mapping of migration, Tuberculosis and Silicosis should be conducted with greater rigour.

**The current mapping does not also bring the association of TB and Silicosis to sectoral issues like mining, migration, displacement which are all high risk sectors for prevalence of these two diseases.**

**There is a need to conduct immediate comprehensive health assessment and inclusion in tribal sub plans** as well as special purpose funds like the DMF. **Particularly, MGNREGS needs to be immediately implemented with focus on tribal population** being included in such pockets where non-tribal groups dominate all schemes, forcing tribals to resort to migration.





***The state tribal welfare department needs to take the lead and undertake an immediate action programme to identify and monitor the implementation of these interventions and bring convergence of other departments in both Scheduled and Non-Scheduled Areas in consultation with the Gram Sabhas.***



## Rehabilitation in Development Projects Must Be Sustainable

The PTR affected villages require urgent review and assessment to complete a fair process of rehabilitation. Even after 15 years of relocation, many basic amenities have not come in and livelihoods have been badly affected, pushing them further into hazardous mine labour and migration. Locally sustainable livelihoods and access to community forest lands, creating more co-existence models of conservation that make local tribal communities included in biodiversity protection and eco-systems regeneration that work to their benefit and that of the wildlife have to be strongly encouraged.



***The Forest Rights Act remains unimplemented and compensation for lands taken has not been fairly conducted.***



There are many pending grievances, relocation sites have new challenges of land grabs from non-tribals and basic infrastructure for women and children are still absent. Child labour has to be urgently arrested with alternate livelihood support for tribals, rehabilitation of child labour, extension programmes like residential facilities for children of migrant families and forest based skills promotion for food security are long pending representations for which **NRLM, Bundelkhand special purpose funds, DMF and TSP funds should be productively and transparently utilised in order to break the vicious inter-generational web of illegal mine labour.**

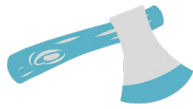
**A more holistic approach to forest conservation and eco-systems services is urgently required where local communities are recognised as primary actors in the coexistence of wildlife and tribals, as the latter are the primary custodians of the forests and have traditional Nature based Solutions that are most effective in bringing back the ecological equilibrium.**

## Caregivers and Energy Rehabilitation

Women are the last mile energy users, yet their access to basic energy needs of cooking has become much more challenging after restrictions in the PA and the diamond mining in the forest.



***Women are denied entry into their community forest lands also because of the growing afforestation plantations like CAMPA whereas deforestation for mining operations is given consent.***



This has added to the burden of housework to the caregivers. While distancing them from the use of firewood has become an objective of most climate action programmes (including the Green India Mission and Ecosystems Services project financed by the World Bank in Panna district itself), these alternate solutions have been too scattered and ineffective to make any sustainable change to women's cooking needs. Rather, they have become a violation of women's rights despite climate funds being stated to have gender policies and operational guidelines for protection of indigenous peoples. None of the Gond women in the study villages received any alternate cooking devices. Instead, women have been criminalised, adding to their hours of work and mental trauma. **Effective use of the DMF funds to create locally sustainable alternatives whether renewables or clean technologies would save these mining af-**



*Women returning after collecting firewood*

affected women from struggling with degraded landscapes of mining and restrictions of entry in PAs. Just restoration to women in mining regions includes just and accessible energy, potable drinking water and rights to access their forests to strengthen their local livelihoods. Denying these basic sustainable development amounts to a serious breach of gender justice and equity, and leading to gender based violence at domestic and

structural levels. Climate finance and Just Transition frameworks need to be assessed from the dimension of entitlements in order to understand whether alternatives or conservation/afforestation programmes are inclusive of communities and their food security. Periodic Gender Audits of these programmes have to be built into these programmes through inclusion of affected women.



*A woman drawing water from a handpump in Umrvan village*

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## Glossary of Terms

**AIGGPA** - Atal Bihari Vajpayee Institute of Good Governance and Policy Analysis.

**ASHA worker** - Accredited Social Health Activist

**Ashwasan/TB Free Tribal India** - the Ashwasan campaign was launched in January 2022, to reach 10 million tribal people in all the blocks across 177 tribal districts, over a 100-day period.

**BHV** - Barefoot Health Volunteers

**CAMPA** - Compensatory Afforestation Fund Management and Protection Authority

**COVID-19** - SARS-CoV-2 (2019-nCoV) coronavirus.

**DGMS** - Directorate General of Mines Safety

**DMF funds** - District Mineral Foundation (DMF) funds

**DOTS intervention** - Directly Observed Therapy Short Course (DOTS) - composed of five distinct elements: political commitment; microscopy services; drug supplies; surveillance and monitoring systems and use of highly efficacious regimens; and direct observation of treatment.

**Gond** - The Gondi or Gond or Koitur are a Dravidian speaking ethnolinguistic group in India. Also fall under the Scheduled Tribe social group.

**Gram Sabha** - Self governing village council as constitutionally recognised under the Panchayats (Extension to Scheduled Areas) Act/PESA.

**HIV** - HIV (human immunodeficiency virus) is a virus that attacks the body's immune system. If HIV is not treated, it can lead to AIDS (acquired immunodeficiency syndrome).

**Mahua flower/tree** - Madhuca longifolia is an Indian tropical tree found largely in the central, southern, north Indian plains and forests

**MGNREGA** - Mahatma Gandhi National Rural Employment Guarantee Act

**NGO** - A non governmental organization

**NHM** - National Health Mission

**NHRC** - National Human Rights Commission of India

**NFHS** - National Family Health Survey

**NMDC** - National Mineral Development Corporation (NMDC), a Public Sector Enterprise under the Ministry of Steel, Government of India

**NRLM** - National Rural Livelihoods Mission (NRLM) was launched by the Ministry of Rural Development (MoRD), Government of India in June 2011.

**NSP** - National Strategic Plan - The NSP for TB elimination 2017–25 is a framework to guide the activities of all stakeholders whose work is relevant to TB elimination in India.

**NTFP** - Non-timber forest products (NTFPs)

**Panchayat** - Village governing institution

**PAs** - Protected Areas

**PDS rations** - Public Distribution System (PDS) evolved as a system of management of scarcity through distribution of foodgrains at affordable prices.

**PHC** - Primary Health Centre - state-owned rural and urban health care facilities in India

**PMKKKY** - Pradhan Mantri Khanij Kshetra Kalyan Yojana (PMKKKY)

**PMTBMA** - Pradhan Mantri TB Mukta Bharat Abhiyan

**PVTGs** - Particularly Vulnerable Tribal Groups - a sub-classification of Scheduled Tribe or section of a Scheduled Tribe, that is considered more vulnerable than other Scheduled Tribes.

**RTE Act** - Right To Education Act(2009). An Act to provide for free and compulsory education to all children of the age of six to fourteen years

**SCs** - Scheduled Castes in India

**Silicosis** - Silicosis is a long-term lung disease caused by inhaling large amounts of crystalline silica dust.

**ST/Adivasi/Tribal** - Scheduled Tribes in India

**TB** - Tuberculosis

**TSP funds** - Tribal Sub Plan funds

**VHSNC** - Village Health Sanitation & Nutrition Committee (VHSNC)

**WHO** - World Health Organization

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