

Silicosis in Rajasthan: A Case Study

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Source:

Photographs number 1, 2 and 5 are taken by the investigator

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Disclaimer: *The persons shown in the photograph 3 and 4 are not this study subjects*

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Acronyms

AKT	Anti-tuberculosis drugs kit
BOCW Board	Building and Other Construction Workers' Board
CDC	Centre for Disease Control
CHC	Community Health Centre
CSR	Corporate Social Responsibility
DALY	Disability Adjusted Life Years
DoL	Department of Labour
ESI	Employee State Insurance
FWA	Federal Wide Assurance
GOHNET	Global Occupational Health Network
GoI	Government of India
GoR	Government of Rajasthan
GPES	Global Programme for the Elimination of Silicosis
ICMR	Indian Council of Medical Research
IIHMR	Indian Institute of Health Management Research
ILO	International Labour Organisation
IRB	Institutional Review Board
LDMS	Labour Department Management System
MoL	Ministry of Labour
MPH	Master in Public Health
NGO	Non-Government Organisation
NHRC	National Human Resource Commission
NIMH	National Institute of Miners' Health
NIOH	National Institute of Occupational Health
NPES	National Programme for the Elimination of Silicosis
OSH	Occupational Safety and Health
OOP	Out of Pocket
PB	Pneumoconiosis Board
PMF	Progressive Massive Fibrosis
REHAB	Rajasthan Environment and Health Administrative Board
RSBY	Rashtriya Swasthya Bima Yojna
SA	South Africa
SHG	Self Help Group
TB	Tuberculosis
USA	United States of America
WHO	World Health Organisation

Abstract

The state of Rajasthan, India is blessed with natural resources, mine, and minerals but the miners/workers involved in the work are suffering from lung diseases and living a miserable life. This study aimed to provide the information/insights about the life of silicosis victims/sufferers to the stakeholders who are involved in silicosis program/ policy/ schemes/implementation and to generate attention and efforts to bring out a positive change and bring benefit to the silicosis victims/sufferers. The objective of the study is to review the literature and government schemes on silicosis, to understand the awareness of silicosis among silicosis victims/sufferers, their attitude towards the disease and its related diseases, and utilization of healthcare services by them. Analysis of government plan/schemes was done as part of literature review and secondary data. Six silicosis patients confirmed by Pneumoconiosis Board and registered under 'Building and other Construction Worker (BOCW) Welfare Board' were interacted. To synthesize the thematic cores, the inductive thematic analysis technique was used and thematic cores such as explanations attributed to the disease, severity of the disease and its consequences, awareness of silicosis and its related diseases, financial implications of the disease, consequences of the disease that impacted their social lives were inferred. According to these patients, the disease was an outcome of their exposure to stone cutting, stone grinding and stone carving work, and their ignorance about the disease. All of them have been exposed at an early age. The disease made the poor workers working in an unorganized sector poorer. Some left treatment because of having no money or meagre means to stay life connected.

The diagnosis of this silicosis (fibrotic lung disorder), caused by inhalation, retention, and pulmonary reaction to crystalline silica has had not been easy and is likely to be confused with tuberculosis which is curable but silicosis once set in is not curable. The disease is preventable if strict preventable measures are implemented. There is a need for a national level programme

to control and eliminate silicosis which can give direction and guidance to all the stakeholders involved. The states are required to make policy/scheme in line to prevent, cure and to provide compensation payment for the workers of unorganized sector. Public awareness generation and prevention programmes based on participatory approach should be started in the language the victims understand.

Background

Silicosis, an occupational lung disease is caused by the inhalation of respirable dust containing crystalline silica as per Centre for Disease Control (CDC) (1). Two forms of the disease are Nodular silicosis (chronic and accelerated) and Silicoproteinosis (acute silicosis). Nodular silicosis progress slowly and manifests as scarring of the lung tissue. Chronic silicosis is typically evident on chest x-ray only after 10 or more years of exposure but accelerated silicosis may be seen after as little as five years. Nodular silicosis may present without symptoms such as shortness of breath and cough which typically comes with an advanced disease. Silicoproteinosis (acute silicosis) which is a less common form of silicosis, is an alveolar filling process which becomes evident within weeks to months after a very intense initial exposure followed by death which usually occurs within a few years of onset (2).

Silicosis is one of the most fatal and most common occupational disease. Major silicosis prone industries are stone quarries and crushers, quartz mining, foundries, sand blasting, ceramics industries, gem cutting and polishing, slate pencil industries, construction, all mining industries, and glass manufacture industries. Inhalation of silica dust results in irreversible lungs fibrosis. Silica exposure is also a major reason for development of pulmonary tuberculosis (co-morbidity). Silicosis usually develops only after decades of repeated exposure to high concentrations of silica dust as it has a relatively long latency period. Silicosis is often confused with tuberculosis due to radiological resemblance but tuberculosis is commonly developed in silicosis patients. Early diagnosis for shifting the potential candidates to safe

modes of workplace as well as for prevention of further progression is the cornerstone of management.

Silicosis is widely spread in most parts of the world and millions of workers are exposed continuously, having a high risk of developing this incurable disease. As per some epidemiological studies, up to 30-50 percent of primary industries and high-risk sector workers in developing countries may suffer from silicosis and other related diseases (3). The increased incidence of tuberculosis with an increased severity of silicosis has also been noticed (3). According to the World Health Report of 2002, an estimated 3,86,000 deaths and approximately 6.6 million disability-adjusted-life-years (DALYs) occur yearly due to exposure to occupational airborne particulates which is an important cause of death and disability worldwide (3).

In USA, 1.7 million of workers are potentially exposed to respirable crystalline silica in different occupations (construction, sandblasting, and mining) in various industries (4). Silicosis is widespread in developing nations. In Asian countries, China recorded more than 5,00,000 silicosis cases during 1991-95 including 6000 new cases and more than 24,000 deaths per year (4). Brazil had more than 4500 silicosis patients (all workers) in one state (Minas Gerais) (4). In Brazil, the estimated population working in organized sector which is exposed to silica for 30 percent of their working hours is approximately 2 million (4).

The main challenge in Rwanda about occupational diseases is silicosis according to one survey conducted in 2003 (4). In Latin America, 37 percent of miners are affected by silicosis and an estimated 1.8 million workers in Columbia are at a risk of developing silicosis as per the Columbian government estimation (4). In US, > 1.7 million workers are exposed to free crystalline silica dust daily including 1,00,000 sandblasters (4). According to the US

department of Labour (DOL) 300 people die every year because of silica related disease, although the exact numbers is not known (4).

India is no exception as the problem of silicosis is prevalent in many states. According to ICMR (1999), about 30 lakhs workers are at a high risk of exposure to silica in different silicosis prone industries (17 lakhs in mining/quarrying activities, 6.3 lakhs in glass and mica industry and 6.7 lakhs in metals industry in the country. In addition, 53 lakhs construction workers are also at the risk of silica exposure (5).

Rajasthan is rich in white and bright wollastonite which is primarily used in ceramics, plastics and as a paint filler, lead, zinc, calcite as construction material, gypsum, rock phosphate to make organic manure, silver, marble, sandstone and serpentine or green marble, dolomite, emeralds, and gamets. The state is the repository of the gigantic slabs of stone accounting 65 percent of the country's stone production and 90 percent of the marble, slate, and sandstone production. In 2000-01, Rajasthan exported stone of worth 2324 million rupees (estimated) (6).

Rationale

Silicosis, one of the oldest occupational diseases is incurable, irreversible, and progresses even when the exposure is discontinued. Prevention is the only treatment of silicosis. The state of Rajasthan is having 42 major and 28 minor minerals and provides employment to about 2 million mine workers in mining sector (6). Silica prone areas in Rajasthan have been identified in 19 Districts and 33 CHCs (7). The approximate number of certified silicosis patients in Rajasthan is over 8000 as reported by Times of India March 8, 2017 (8). The diagnosis of silicosis is not easy and often it is confused with tuberculosis, which is curable but silicosis is not. Most papers found in literature review were based on disease incidence, clinical aspects of developing the disease, pathology, associated diseases, but none of the paper discussed the financial schemes available in the country for silicosis patients and presented the disease from

the patients/sufferer's point of view, their level of awareness, attitude towards silicosis and utilization of healthcare services by these patients, which justifies this study.

Aims

Study aimed to provide the information/insights about the life of silicosis victims/sufferers and the difficulties faced by them, to the stakeholders who are involved in making silicosis program/ policy/ schemes hoping that it would bring a positive change in the current silicosis scenario and bring benefit to the silicosis victims/sufferers.

Objectives

1. To review the literature and government schemes on silicosis.
2. To study awareness of silicosis among silicosis victims/ sufferers and their attitudes towards silicosis and related diseases
3. To study utilization of healthcare services by silicosis victims/sufferers

Methodology

Some studies/papers on silicosis during the literature review were found. Large scale epidemiological studies on silicosis in India is lacking (9). Literature review shows that there is a definitive link between high exposure to crystalline silica and silicosis (10) and once the disease is developed the patient should avoid all source of exposure (11). One study mentioned the vast number of men approximately 2,80,000 eligible for occupational health compensation in South Africa indicating the magnitude of occupational risk hazard in South Africa and the study also mentioned the cumbersome process of providing compensation to the workers (12). Some studies suggested that silica dust exposure is a significant risk factor for Tuberculosis (TB) too (12). The other important factor which emerged out of the review of South African 'National Programme for the Elimination of Silicosis' is that not only silicosis but exposure to silica dust also a factor for increased risk of tuberculosis and this risk persists for lifetime even

when the exposure ends. Tuberculosis itself, is a very damaging disease particularly for rural poor. The fact that intersectoral convergence is necessary to run a national level elimination programme is necessary has emerged out after SA policy review (13).

In India, only three states have taken steps to deal with the growing issue of silicosis and Rajasthan is one of the states (14).

During the development of this project paper the literature, reports, studies available on the subject matter were reviewed. Search was conducted on electronic media using 'Google Scholar', 'PubMed', 'ProQuest, world wide web and key words like Silicosis and Policy, schemes, were used. Articles containing the key words 'silicosis, policy, schemes were selected. Articles were included if they described silicosis, policy, schemes related to silicosis, and case studies along with the related reports of WHO. The relevant grey literature, unpublished commissioned research, editorials, and policy documents, as well as instruments used in silicosis prevention were also retrieved and studied. Analysis of the policy/scheme was done as part of review of literature and secondary data.

To meet the other objectives of the study and to have the first-hand insights on their life after silicosis, six nearby confirmed silicosis victims/sufferers were decided to be interacted with. Victims were defined as adult (18 years of age and above) individual silicosis patients with or without other silicosis related disease as diagnosed by doctors. Sufferer as family members of these victims.

Inclusion criteria included confirmed silicosis patient (silicosis and/or silicosis related disease)/victims or sufferers, 18 years of age and above, those who are willing to participate. Patient/victims or sufferers were excluded from the study if not of sound mind and able to answer, or did not want to take part in study after getting consent.

Based on the assumption that disease experience is personalized and people view the disease in the light of their personal experiences, and knowledge, this study is based.

Eight patients from three different blocks of Dausa were selected to be interacted with. One did not receive our call, another one was out of station so finally six confirmed silicosis patients (silicosis, with or without silicosis related disease)/ victims or sufferers, 18 years of age and willing to participate were interacted in Sikandra and Manpur blocks of district Dausa, Rajasthan at their (patients) convenient places. These patients were interacted to understand the awareness about silicosis among silicosis victims/sufferers and attitude towards silicosis and related diseases and utilization of healthcare services by them. All these patients were registered under BOCW Welfare Board, Department of Labour, Government of Rajasthan and silicosis confirmed by Pneumoconiosis Board, Rajasthan. The guiding probes like occupation details about previous and present, reason for exposure for these occupation, awareness of silicosis and its related disease, money spent on treatment, effect of silicosis on the patient and their families, friends, neighbours attitude towards them because of this illness, and did you get any financial help for this disease were asked. In addition to these questions, I sought to differentiate the participants in terms of education, income, age, marital status, and number of dependants.

The verbatim were transcribed verbatim, information were organized and inductive thematic analysis was done. Analysis was done starting by thorough reading of the entire material, reading of each text to identify similarities, differences, and details of narratives, classifying them into codes was done. The content (gathered information) was initially classified into socio demographic information (age, sex, marital status, number of dependents, economic status etcetera), occupational information (occupational details past and present, reason for exposure to this occupation, awareness of silicosis & its related diseases (signs and symptoms, treatment, employment), medical information/healthcare (illness details related to past and present, diagnostic process, medication, hospitalization etcetera), money spent on treatment (direct and

indirect), effect of silicosis on patient and his/her family, friends etcetera, and compensation or financial help received.

Afterward, thematic cores such as explanations attributed to the exposure, awareness of silicosis & its related disease, explanations attributed to the disease, severity of the disease and its consequences, financial implications of the disease, and consequences of the disease that impacted their social lives were derived. The participants narratives are presented in between the report. Fictitious names identify the patients here, their age is also included to show their phase of life. The inductive thematic analysis technique was used.

Probes were used to explore the issues related to symptoms, disease, patients level of knowledge about disease, healthcare services they seek and to understand their needs in current context. People's knowledge and interpretation of a disease is based on their personal experiences and the various means through which they acquire this knowledge. Elements such as when and how the symptoms appeared, treatment seek and the financial support they got were asked.

This study was conducted after the approval and ethical clearance obtained from Institutional Review Board (IRB) under Federal Wide Assurance (FWA) for the Protection of Human Subjects of Indian Institute of Health Management Research (IIHMR) University, Jaipur, Rajasthan.

Results

Review of secondary data revealed that the magnitude of silicosis worldwide and endemic states of India is high. Rajasthan is one such state. Studies are required to be conducted in the country as very few studies were found. A central authority in states who could deal with the situation comprehensively is missing. Inadequate measures have been taken by the governments. The findings of the primary data based on interaction with the silicosis victims/sufferers revealed that silicosis has greatly affected their lives not only financially but

their social life, and the lives of their families too. These victims do not have adequate resources to meet the daily requirements of themselves and their family. In the absence of a financial scheme these workers of an unorganized sector suffer greatly and stop taking treatment because of the lack of money. Families which were having a decent meal before the onset of the silicosis to the bread winner of the family are forced to consume inadequate food.

Silicosis Scenario Globally

Silicosis is commonly found globally affecting millions of workers who are exposed continuously, having a high risk of developing this deadly disease. In China, 5,000 deaths occur annually due to silicosis. On an average 60,000 new cases have been detected during 1991-95 and 1,000,000 cases diagnosed by 2002. In Latin America, silicosis prevalence rate is 37 percent (9). The status of silicosis in US, Germany, France, Japan, Australia, and United Kingdom can be seen from **Table 2**. The magnitude of the disease is huge in developing as well as developed countries in term such as economic burden, loss of productive years of a person's life, and other social implications (9).

Table 1: Global Scenario of Silicosis: China, Latin America and South Africa (9)

Country	Case Detail
China	➤ 60,000 New Cases (1991-95) ➤ 1,000,000 cases diagnosed by 2002 ➤ 5,000 deaths due to Silicosis every year ➤ 10 – 15,000 new cases of Silicosis every year
Latin America	➤ 37% Prevalence rate of Silicosis in mines
South Africa	➤ 600,000 cases of Silicosis diagnosed by 2000 ➤ 30 - 50% Prevalence in mines

Source: Sishodiya PK. “ Occupational Health Legislation : need for innovative approach. ”

Source: Learnt TL. Directorate General of Mines Safety Inquiry about Silicosis

Table 2: Global Scenario of Silicosis: USA, Germany, France, Japan, Australia, and UK (9)

Global Scenario of Silicosis	
USA	1.7 million workers exposed and 10% at risk
Germany	3,000 new cases of silicosis annually (1990s)
France	300 new cases of silicosis are notified yearly
Japan	1,000 new cases of Silicosis reported yearly
Australia	1,010 (range 380-2410) new cases are predicted
UK	1,164 new cases of Pneumoconiosis

Source: Sishodiya PK. "Occupational Health Legislation : need for innovative approach"

Source: Learnt TL. Directorate General of Mines Safety Inquiry about Silicosis

Table 3: Cases of Pneumoconiosis compensated in South Africa (2002-2004)

Mineral	2002	2003	2004	Total
Gold	2204	2168	997	5369
Platinum	51	109	84	244
Coal	58	58	55	171
Asbestos	167	3486	207	3860
Other Mines	119	117	126	352
Total	2599	5938	1469	9996

(Draft Report: SIMRAC Silicosis Elimination Programme, National Institute for Occupational Health (NIOH), South Africa Project number: SIM 030603)

Source: Revised Occupational Health Legislation, NHRC_PKS (9)

Silicosis Scenario in India

There are many known industries linked to silica exposure such as construction, mining, agate polishing, cement manufacturing, foundry work (grinding, mouldings, shakeout etcetera). stone cutting (chipping, sawing, grinding, abrasive blasting), glass manufacturing and slate pencil in the country. The silicosis situation is a serious concern as the disease continues to be the reason of thousands of deaths annually. There is also the three-fold risk of developing tuberculosis in workers having silicosis. The actual number of deaths (mortality) due to silicosis is not known as reliable statistics are not available (9) (15).

The reliable data on silicosis morbidity and mortality (official statistics) is not available in India. Large scale epidemiological studies are missing on the subject (16). As per the latest report of NHRC on silicosis, the number of deaths due to silicosis are large but no statistics available concerning these deaths. In 22 States/UTs of India, dangerous industries (silicosis prone) exist (7). These States/UTs are Andhra Pradesh, Assam, Chhattisgarh, Daman & Diu, Delhi, Goa, Gujarat, Haryana, Himachal Pradesh, Karnataka, Kerala, Madhya Pradesh, Maharashtra, Odisha, Puducherry, Punjab, Rajasthan, Tamil Nadu, Tripura, Uttar Pradesh, Uttarakhand, and West Bengal. As per one NIOH (National Institute of Occupational Health) report, large number of workers (approximately 10 million) are at the potential risk of exposure to silica (crystalline free silica) in the country. Gujarat, Jharkhand, Madhya Pradesh, Rajasthan, Karnataka, and West Bengal are the endemic states (7).

a) Problem of Silicosis in Indian Factories

The prevalence of silicosis in different silica related industry is high as it could be seen from below **Table 4**. The prevalence is 54.7 percent in Slate Pencil industry and 41.7 percent in Quartz grinding. The silicosis patients that were interacted for this study revealed that they were involved in stone grinding for a number of years and then moved to other related work (statue making, stone carvings, designing on stone etcetera) (16).

Table 4: Prevalence of Silicosis in different Silica industry

Industry	No. of Persons Examined	Cases of Silicosis	% of Silicosis
Slate Pencil	593	354	54.7
Ceramic	292	44	15.7
Agate Grinding	468	136	29.1
Stone Cutting	89	17	19.1
Quartz Grinding	218	91	41.7

Source: Sishodiya PK. “ Occupational Health Legislation : need for innovative approach ”

b) Problem of Silicosis in Indian mines

Silicosis survey in Kolar Gold Fields (1940-46): Silicosis was detected in 3402 (43.7 percent) of cases out of the 7653 examined (16).

Table 5: Prevalence of Silicosis in Indian Mines' workers

S. No.	Mines	Organisation	Year	No. of Persons Examined	Cases of Silicosis	% of Silicosis
1.	Kolar Gold Fields	Chief Advisor of Factories	1940-1946	7643	3402	43.7
2.	Mica		1953	329	112	34.1
3.	Manganese	Directorate General of Mines Safety	1960	243	10	4.1
4.	Lead & Zinc	Chief Advisor of Factories	1961	171	52	30.4
5.	Lead & Zinc		1962	273	71	26.0
6.	Iron Ore	CMRS & Directorate General of Mines Safety	1968	177	42	23.7
7.	Mica	Directorate General of Mines Safety	1976	110	19	17.2
8.	Stone	National Institute of Occupational Health (NIOH)	1995	416	41	9.9
9.	Gold	Directorate General of Mines safety	2001	4883	313	6.4
10.	Zinc		2002	441	131	29.6
11.	Uranium		2002	91	9	9.9

Source: Sishodiya PK. "Occupational Health Legislation : need for innovative approach ."

Source: Learnt TL. Directorate General of Mines Safety Inquiry about Silicosis.

c) Result of the survey done on unorganised migrant workers in 3 Tribal Districts (Alirajpur, Jhabua, and Dhar) of Madhya Pradesh, India

Survey undertaken in 102 villages revealed 1701 victims of silicosis out of which 538 (1/3rd) are dead due to exposure between 1983 to 2011. 11 percent (185) of victims were children and

216 children lost one or more parent. 55 percent of victim families were either landless or owned < 1 acre of hilly rainfed land In 78 percent families breadwinner got disease (17).

d) Silicosis in Sikandra, Dausa, Rajasthan

NIMH sent > than 300 Chest radiographs from Dausa, Sikandra and nearby area for expert opinion. The prevalence rate of silicosis was found 30- 35 percent (16).

Table 6: Prevalence of Silicosis in Dausa Stone Cutters

Dausa Stone Cutters					
➤ NIMH received 135 chest radiographs of stone cutters from DVS for evaluations, Chest X-rays of 88 persons were evaluated. ➤ 53 (60%) had evidence of silicosis and 4 (4.5%) of them had developed PMF ➤ 10 persons showed radiological evidence of pulmonary tuberculosis (82 persons received AKT)					
Age Group	No. of Persons	Silicosis			
20-30	24	13	47 (88.7%)		
31-40	54	34			
41-50	09	6			
51-60	01	0			
Total	88	53			
➤ 78 persons out of 88 are in the age group of 20-40, ➤ 47 out of 53 cases of Silicosis are in this age group					
Years of Work	Silicosis	PMF	Total No. of Persons	Category of Silicosis	No. of Persons
< 10	05 (41%)	0	12	Cat- 1	12 (22.5 %)
11-20	35 (60%)	2	58	Cat- 2	25 (47.2 %)
21-30	13 (72%)	2	18	Cat- 3	16 (30.3 %)
>30	0	0	0	Total	53
Total	53 (60%)	4	88		

Source: Sishodiya PK. "Occupational Health Legislation : need for innovative approach"

Source: Learnt TL. Directorate General of Mines Safety Inquiry about Silicosis

Policy Analysis

There is no national health program or policy on silicosis is running in India. Silicosis is incurable but the disease is preventable. In Rajasthan state, Silicosis detection and treatment is organised by District TB Officer in camps. Pneumoconiosis Boards which certify the disease

have been established in some medical colleges of the state. District collector is supposed to take regular periodic meetings about silicosis monitoring (9).

Provision of compensation for Silicosis victims in India

As per ESI act and the Workmen's' Compensation Act, silicosis is a compensable injury, therefore required a separate Silicosis Board to deal with it. Odisha government has set up such board but this has not been formed on in other states. The purpose of the board is to carry out surveillance of silicosis cases and assessment of disability/loss of earning capacity resulting from the diseases for compensation and rehabilitation purposes. The Government of Rajasthan has taken an initiative to declare silicosis as a notified disease under the Rajasthan Epidemics Act, 1957. Rajasthan Environment and Health Administrative Board (REHAB), Government of Rajasthan pays ex-gratia payment of Rupees 1 Lakh to a silicosis affected person and Rupees 3 Lakh to the dependents of the deceased (20) (21).

Where does India stands in terms of a National Program/ National Policy/National Plan/ Schemes on Silicosis: Legislative provisions

Silicosis is the oldest known occupational health hazard/ disease to mankind but unfortunately the disease has not been the focus of the healthcare policy makers or providers. Although the queries related to the silicosis have been asked in Lok Sabha and Rajya Sabha from time to time (18). Ministry of Labour (MoL), GoI has forwarded one draft national plan on silicosis but presently no known national plan, policy or programme on silicosis is finalized or in implementation in the country. As such no central authority has been formed by the government to coordinate the efforts done by various ministries, departments, institutions and other stakeholders in the control and prevention of the disease (15).

a) Constitution of India

The health, safety, and welfare is the constitutional rights of the individuals who are involved in various occupations. The Constitution of India give provisions for ensuring health, safety, and welfare of persons employed in various occupations. Employment of child <14 years for work in any factory or mine or in any hazardous employment is prohibited by Article 24. Article 39 gives directions to the states to ensure that the health and strength of workers, men and women, and the tender age of children are not abused and that citizens do not enter in occupations forced by economic necessity which are unsuited to their age or strength and as per Article 42, states are required to make provision for securing just and humane conditions of work and maternity relief (15).

b) Statutes/Provisions for Silica exposure and Silicosis under various Legislations

There is no specific statute in the country, specifically for silica and silicosis which is covered by Occupational Health and Safety legislations. Statutes related to Occupational safety and Health (OSH) in relation to silica exposure and silicosis are divided into three statutes **i)** Factories Act, 1948 administered by state governments for health, safety, and welfare of workers at workplaces and Mines Act, 1952, concern of the Central Government, **ii)** Indian Explosives Act, 1884 for safety of substances, **iii)** Radiation Protection rules under the Atomic Energy Act for safety of activities.

c) Role of National Human Rights Commission (NHRC) in Silicosis

The National Human Rights Commission (NHRC) of India was established on 12th October 1993, with an aim to promote and protects the rights of humans. The commission has brought silicosis on record for the first time in 2009-10 when its team detected 74 silicosis cases. These cases include 22 deaths due to the disease. The ex-gratia payment of Rupees 3 Lakh each to the dependents of the deceased has been given by the Government of Rajasthan's Chief Minister Relief Fund (7).

The Supreme Court of India in 2009 observed that "the NHRC may take up the specific and confirmed cases of persons who are suffering from silicosis and shall recommend to provide immediate medical relief to them through the concerned authorities and in case of death of these persons because of silicosis, may provide for compensation through the concerned authorities." (7). Afterwards, NHRC constituted an 'Expert group on Silicosis' to assist in devising strategies to deal with silicosis and to evolve necessary preventive, remedial, rehabilitative measures to alleviate the problem in the country.

The Supreme Court of India, in certain cases guided the states, recently the court directed the state government of Gujarat to pay relief to 238 victims of silicosis or their next of kin. The supreme court also directed the state of Madhya Pradesh to rehabilitate 304 silicosis affected people as pointed out by NHRC in 2010 (7).

Worldwide National Programs on Elimination of Silicosis (NPES)

The ILO/WHO Global Programme for the Elimination of Silicosis (GPES)

International Labour Organisation (ILO) and World Health Organisation (WHO) have established Global Programme for the Elimination of Silicosis (GPES) in 1995, which is an international technical cooperation programme for the elimination of silicosis. GPES is based on policy perspective for a wide international collaboration between developed countries, developing countries and international organizations. Under this program, countries are required to set up National Programmes for the Elimination of Silicosis (NPES) which should provide recommendations for the necessary elements of NPES and national silicosis profile. NPES have been established in Brazil, Chile, China, India, Peru, South Africa, Thailand, Turkey, and Vietnam till date. It is on the roll in many other countries (19).

Findings based on the information collected during interaction

Below mentioned findings are based on the information collected during the interaction with six confirmed silicosis patients from two blocks of District Dausa.

Case Studies: Sikandra, Manpur, District Dausa, Rajasthan

a) Social Profile

Participants characteristics in relation to the social context are presented to better understand the overall consequences of the disease.

All the participants were male between the age group of 24 to 50 years. Four participants were aged between 24 and 33 years old (66.70 percent), and two between 34 and 50 years of age (33.30 percent). All of them were married. Out of the six, in relation to education, three (50 percent) have incomplete primary school education, one (16.66 percent) completed primary school, one (16.66 percent) was illiterate and one (16.66 percent) the youngest one was a graduate. These social characteristics are similar to the characteristics found in other country studies/literature review (Brazil) (22).

50 percent of these participants were not earning at the time of the interaction because of the severity of the disease. They were dependent on the help from relatives. The rest 50 percent participants' income from all means ranged from Rupees 2000-5000. Number of dependent (adult/children) vary from none to seven. Out of six, one person was not responsible for any dependant. One person was having the maximum number of dependants (seven) and was not even in a condition to be employed anywhere because of the severe condition of the health due to silicosis. Out of the rest four patients, two were having 6 dependants, and one each was having five and four dependants. All of them have been in the same occupation since starting point. The social profile of all these participants disclosed that they all belonged to the different rural areas of Dausa from low income group, low education level (except one), early exposure to this work because of their parents, relatives were in the same occupation/work, and the development of the skill early in this work led them to stay in the same occupation and ultimately poor financial conditions because of the development and severity of the disease working under poor working conditions.

b) Explanations attributed to the exposure

All of them have been involved in the stone cutting, stone grinding, stone polishing, stone carving and designing, stone statue making, and other related activities during their entire work life. At the time of the interaction, all had left this occupation except one who worked irregularly whenever his health permitted in the same work area because he knew only this work although he knew since last 12 years that he has silicosis. All of them have been exposed early in their life (adolescent) one each at the age of 14, 15, 17, 20 and two at 16 years. They have been continuously exposed to these conditions for 8 years to 20 years meaning out of six persons, one each (16.66 percent) has been exposed to 8 years, 15 years, 17 years, and 20 years while two (33.33 percent) were exposed for 13 years. The length of the time that they worked in this stone industry until the time they have their confirmed diagnoses varied from 6 years to 14 years. One each (16.66 percent) has confirmed diagnosis after exposure to 6 years, 10 years, 11 years, 14 years, and two persons (33.33 percent) after 13 years. The youngest person (24 years old, a graduate) have his confirmed silicosis diagnosis after exposure to least (6) continuous years. Their deteriorating health conditions made them quit their job/ occupations. Two patients left the work since last two years, one each since last one year and less than a year and one since last three years. They worked while they knew that they are silicosis patients. The number of work years varied from half year to 4 years since they came to know about their disease. One person still works in the same field whenever his health permits although he knew since last 12 years that he is suffering from silicosis. All of them have told that their energy level is low all the time and they are not able to do any work and they feel breathlessness even when walking. These characteristics, also indicates that the opportunities in the job market for these persons are limited.

c) Explanation for the disease, symptoms, and diagnoses

All the respondents told about the same sign and symptoms. In the beginning of the disease, pain in lungs, breathing problems, breathlessness, pain in chest and back, coughing, and the loss of energy in body. Presently, they all knew that they are suffering from silicosis because of the nature of work they had been involved into. They did not know that at the time when they started working in this industry. They were ignorant and later, they either learnt about the disease from other persons involved in the same work or from friends/relative, as one of them put it: [...] *pehle to bilkul maloom nahi tha ki patthar ke kam se ye silicosis beemari hoti ha. Phir logo se suna phir humne bhi jancha us time beemari nahi thi to kaam karte rahe baad me jab takleef hui dedh saal pehle thoda dard lungs me, phir daktar ko dikhaya unhone kaha ki aapko ye beemari hai ye kaam band kardo nahi to takleef zyada hogi* [...] (Vishesh, 28 years old). Some sought medical help when they started coughing and coughing became painful. One-person Naresh (name changed, 43 years) told that he had been diagnosed with typhoid, malaria, and other disease but doctor was not able to tell him that he is suffering from silicosis because it was lesser known disease by then, as he told: [...] *Jaipur janch karwayi thi wahan kaha aapke gurde kharab hogaye hain, phir typhoid bata daya malaria bata diya, kai rog bata diye par ye nahi bataya uss waqt to silicosis koi jan pade hi nahi thi* [...], two patients reported that doctors gave tuberculosis (TB) treatment but not silicosis. Naresh (43 years) started working at the age of 17 years, exposed for 13 years till the time he was confirmed as a silicosis patient. Dausa district is well known for its stone quarries and it's a silicosis prone district of Rajasthan. As the number of silicosis cases became known the doctors as well as workers became more aware of the disease as reported by one patient Devesh (24 years). Devesh started working at the age of 14 years and worked for 8 years in the same stone industry, two years back (after 6 years of continuous exposure) he went to the doctor because he had episodes of dry coughing. The doctor asked about the type of work that he is doing and told him after x-

ray, blood tests, chest x-ray that he is suffering from silicosis and suggested him to leave the work. In this case, Devesh left the job/ occupation since last two years. All the patients revealed that getting the treatment is a costly affair. Initially they (all) have consulted government doctors but when no relief was felt after taking these doctors medicine and they started having blood while coughing they resorted to private practitioners stating that government medicine/treatment did not suit them. All of them have this conception that their body is not able to take up the strong medicine given to them by government doctors. Seeking treatment was stressful for all of them. Sometimes they have to go to the nearby city Jaipur for treatment and tests which was expensive for these poor workers.

All the patients were only diagnosed with silicosis and not with any other related disease.

d) The severity of the disease and its consequences

All the participants shared that the disease has had a devastating effect on their lives. Two respondents Ramesh (name changed, 50 years) and Paresh (name changed, 33 years) said that they cannot walk even a distance of 300-400 meters without taking rest two-three times in between, as one of them put it: [...] *do saal se kaam nahi karta, saans bharta hai jo bhi kam karta hun usse saans bharta hai, daudne se chalne se, yaha thodi door tak chala jaun to teen baar baithta hun, kabhi koi sadhan ho to uspar baith kar jaata hun, kuchh kaam nahi karta, kuchh kar hi nahi pata bas khaat pe pada rehta hun poore waqt [...]* (Ramesh, 50 years old).

They become breathless, feels that they don't have energy in their body and feels difficulty in breathing, pain in chest and ribs. Because of the severity of the disease they were not able to do any work, they just sit at home, sleep, and take rests all the time. The condition of loss of energy has been reported by all the respondents. They were devoid of energy bit by bit and they all knew that their disease is not curable. The disease not only had a devastating effect on their lives but also on the life of their family as shared by one respondent that the family used

to eat better when he was healthy and not now. The interlocutor also observed the feeling of dejection among the respondents.

e) Financial implications of the disease

All the respondents spent their own money on the treatment. Out of pocket expenditure was high on the treatment. Out of six, three patients have been advised by the doctor for hospitalization. Two admitted for 15 days and 2 days respectively. One refused to admit because there was nobody to take care of his family. They spent from Rupees 10,000 to 4-5 lakhs on their treatment. One respondent (Devesh, name changed) said that whenever he has this dry coughing episode he sought treatment and Rupees 10,000 he had to spend on one such trip. Twice he had these episodes in the last 2 years and he spent Rupees 20,000 from his pocket. One (Paresh, the severe case, 33 years) spent Rupees 4-5 lakh on his treatment and now he has left with no money to buy the medicines that's why he has stopped his treatment since last 3 months, as he put it: [...]*dawa chhod di, koi laabh nahi, paisa bhi nahi, chhod di paisa nahi sab log lootan laga diya, 2-3 mahine se chhod di, takleef hoti hai lekin dawa ka paisa hi nahi hai* [...]. Paresh's voice choked during the interaction many times and the interlocutor observed the gloom, despair, and the feeling of helplessness he was feeling.

One respondent (Ramesh, age 50 years, severe case) spent Rupees 35,000 from his pocket even when he was admitted in a government hospital. This was in addition to the money that they were required to spend monthly on their medicines and other requirements. The expenditure on medicines were ranged between Rupees 2000 to 6000 per month. Two persons spent between Rupees 5000-6000, one between Rupees 2000-3000, one Rupees 4000-5000. One was not taking medicines because of no money and one was not asked to take regular medicine by the treating doctor. As a consequence of the disease and their personal expenses on the treatment has made them poorer. All of them were receiving some help from their family,

siblings, relatives, or friends. They have borrowed money from friends, relatives to purchase their medicines.

f) Financial assistance received

Nobody except one had received financial assistance from any side, neither from government, NGOs nor from their employer's side. Only one respondent (Devesh, name changed, 24 years, graduate) has received the financial assistance of Rupees 1,00,000 given by the Department of Labour, Government of Rajasthan. They all have been certified as silicosis patients by Pneumoconiosis Board of Rajasthan. Their applications are pending since many months (6 months) with labour department. One of the patient (Paresh) had even shown the message that he had been receiving from Labour Department Management System (LDMS), GoR which he or the other persons of his village could not understand because it was in english and not in language they can read (hindi).

g) Consequences of the disease that impacted their social life

Four out of six patients were young adult below the age of 40 years, and they developed silicosis after exposure to as early as 6 years. The most productive years of their life have been exposed to the environment most suitable to develop this incurable disease. The disability because of silicosis hindered their growth (financial as well as biological well-being), their working capacity (working is one of the main social function), hit their self-esteem badly as they become dependent on the help and support from others, and the quality of life affected, as one of them put it: [...] *Family madam ekdam pichhad gayi na, kuchh karna chahte they wo bhi nahi hua. Char bhaiyon ki shadi karni hai wo kaise karenge? Rehne ke liye makaan banana hai ye kaun banayega? Aage badhne ke chakkar me ulta peechey aa gaye* [...] (Devesh, 24 years old).

They are not able to live their daily normal routine. Their social life is affected greatly. They generally sit at home throughout the day. Their neighbours and friend keep them afar because

of the fear of getting the disease (coughing and breathlessness, asthma). Their family is not able to have a decent meal because of the lack of money, as one of them put it: [...] *pariwar par 5-6 hazzar ghar ka kharch tha pehle ab 2000 ho gaya, pehle badhiya kha leta tha ab nahi ho pata ab hai hi nahi, padosi bhi kehte hain kuchh dawai lelo, dawai le lo, dawai main le raha hu, pados me nahi baithne dete kehte hai tere ko saans ki beemari hai sabko lagayega* [...]

(Naresh, 43 years old).

Discussion

Silicosis progresses at a low rate over a period of ten to fifteen years but in some cases disease may start early as early as six years of exposure as it has happened in the case of our study's youngest victim (Devesh, 24 years old, started working at the age of 14 years, for 8 years continuously he worked in the same work, he came to know about his disease (confirmed diagnosis) only 2 years back). Breathlessness on exertion and coughing the most common symptoms (as told by our all respondents and also observed by the interlocutor during the interaction) and the physical examination does not show the changes in the respiratory system, it is the diagnostics tests (radiology and pathology) that confirms the disease. All our respondents told that, it started with coughing and pain in chest, tiredness which increased with time, all of them kept working in the same industry so continuously exposed to those silicosis prone conditions. All our respondents revealed that they had been assessed many times and confirmation of the disease were established after repeated test and journey to nearby city which four participants had to take which was again a burden on the patients and their families.

The feeling of being vulnerable was noticed among all the respondents and they have revealed (and observed during discussion too) that they are not educated, poor people, this is the only work that they know and can do, medicine provided at government health facilities do not suit

them, and the feeling of helplessness and powerlessness on their current conditions was also observed.

The respondents also told that the cost of their treatment is high (monthly expenditure on medicines ranged from Rupees 2000-5000) for poor persons like them and the conception that medicines supplied by government healthcare facilities do not suit them (all of them revealed that) which lead them to sought treatment at private healthcare providers which ultimately lead to higher cost of treatment. The repercussions of all the above stated have had a direct effect on the families as these male members were the bread winner of their respective families and sustenance in the absence of the main earning member is not only difficult but takes a toll on the entire family. The increasing debt to meet their treatment expenses as well as fulfilment of the requirement of their responsibilities (all of them except one have adult and children dependents) forced them into not only in the poorer category but in a state of continuous distress. The fact that one of the respondents (Naresh, age 43 years) did not leave/abandon this work even after having the disease for 13 years and knowing that the disease is a killer disease with no cure available currently, showed the helplessness and powerlessness over his circumstances being the only earning member of the family. Except him all of them left their occupation not immediately but after their health status deteriorated.

Conclusion

Review of secondary data revealed that the magnitude of silicosis is high in the country's silicosis endemic states including Rajasthan. Although government have provisions to deal with the growing issue of silicosis but a central authority in states who could deal with the situation comprehensively is missing. Inadequate measures have been taken by the government. The findings of the primary data based on interaction with the silicosis victims/sufferers revealed that silicosis has greatly affected their lives not only financially but their social life, and the lives of their families too.

Recommendations

Recommendations (policy and action) are provided based on the findings of the study.

a) For Government (at National Level & State Level)

- i.** Government needs to take firm steps in the formation of a “National Programme for the Elimination of Silicosis”.
- ii.** These workers could be included in the governments’ run insurance scheme like Rashtriya Swasthya Bima Yojna (RSBY).
- iii.** There is a need for state level program focused for silicosis prevention and elimination.
- iv.** Public awareness generation and prevention programmes based on participatory approach are required to be initiated at the earliest in the language the victims understand.
- v.** Employers and the contractors (highly unorganized sector) should be involved in these programmes to generate awareness as well as responsibility and accountability.
- vi.** State government may involve and encourage the NGOs to take up the issue. Silicosis Self Help Groups (SHG) should be formed.
- vii.** State government may ask/suggest the companies/organizations to work in this filed as part of their Corporate Social Responsibility (CSR).

b) For Employers

- i.** The employer should take necessary measures (dust control systems) to reduce silica dust and implement those measures strictly.
- ii.** The employer should arrange a periodic medical examination of all the employees involved in the establishment and consciously implement precautionary measures.

c) For Employees

- i.** Employees needs to adhere to the precautionary measures to protect themselves while exposed to silica dust.

Limitations

Due to limited resources extensive case study to substantiate the need of a comprehensive policy on silicosis was not undertaken. Some discrepancies were found in the age told by the respondents and the age written on certificate given by Pneumoconiosis Board but the proof of date of birth to verify was not included in our discussion probe so it is considered as a limitation.

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Annexure: IRB Approval

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