## Contents

<table>
<thead>
<tr>
<th>Title</th>
<th>Page No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgement</td>
<td>i-ii</td>
</tr>
<tr>
<td>Contents</td>
<td>iii-vii</td>
</tr>
<tr>
<td>List of tables</td>
<td>viii-vii</td>
</tr>
<tr>
<td>List of figures</td>
<td>xii</td>
</tr>
<tr>
<td>Abstract</td>
<td>xiii</td>
</tr>
</tbody>
</table>

### Chapter 1  
**Introduction, Review of Literature, Data and Methods**  
1-28

1.1 Introduction ................................................................. 1

1.1.1 Tuberculosis (TB) ...................................................... 2

1.1.2 Epidemiology of Tuberculosis ........................................... 3

1.1.3 Tuberculosis Burden in India ........................................... 4

1.1.4 Tuberculosis, HIV/AIDS and Multi-drug resistance: a tri-threat ................................................................. 5

1.2 Literature Review .................................................................. 6

1.2.1 Treatment seeking behaviour of tuberculosis patients .............. 6

1.2.2 Delay and adherence to treatment of tuberculosis .................... 7

1.2.3 Economic burden of tuberculosis treatment ......................... 8

1.2.4 Gender and tuberculosis .................................................. 10

1.2.5 Stigma and Discrimination ............................................... 11

1.3 Need for the study .................................................................. 13

1.4 Objectives of the study ........................................................ 14

1.5 Theoretical background of health seeking behaviour (HSB) .......... 15

1.6 Sampling design ...................................................................... 17

1.6.1 Selection of study area .................................................... 17

1.6.2 Selection of wards ................................................................ 17

1.6.3 Community profile of slums in M-ward ................................ 19

1.7 Data ....................................................................................... 20

1.8 Ethical issues .......................................................................... 21

1.9 Contents of interview schedule ............................................... 21

1.10 Field experience and data collection ..................................... 22

1.11 Conceptualization of used terminologies ................................ 23

1.12 Construction of variables .................................................... 24

1.13 Organization of thesis ......................................................... 28

1.14 Analysis plan ......................................................................... 28

### Chapter 2  
**Surveyed Tuberculosis Patients** ............................................. 29-52

2.1 Introduction ........................................................................... 29

2.2 Household profile of tuberculosis patients .................................. 29

2.2.1 Household profile by gender of patients .................................. 30

2.2.2 Household profile by morbidity status of patients ................... 32

2.3 Living conditions, drinking water sources and sanitation facility .... 33
2.3.1 Living condition, drinking water sources and sanitation facility of household by gender .................................................. 33
2.3.2 Living condition, drinking water sources and sanitation facility of households by morbidity status .......................... 35
2.4 Individual Profile of surveyed tuberculosis patients .................. 35
  2.4.1 Socio-demographic profile by gender .................................. 36
  2.4.2 Socio-demographic profile by morbidity status ..................... 37
  2.4.3 Socio-demographic profile by economic status ..................... 38
2.5 Disease profile of the tuberculosis patients at the time of survey .... 40
  2.5.1 Disease profile by gender ................................................. 40
  2.5.2 Disease profile by morbidity status ................................... 41
  2.5.3 Disease profile by economic status ................................... 42
2.6 Awareness and knowledge gap among surveyed tuberculosis patients ................................................................................. 43
  2.6.1 Awareness and knowledge about TB by gender ................. 43
  2.6.2 Awareness and knowledge about TB by morbidity status ...... 46
  2.6.3 Awareness and knowledge about TB by economic status ...... 47
2.7 Awareness and knowledge about HIV/AIDS among tuberculosis patients .............................................................................. 48
  2.7.1 Awareness and knowledge about HIV/AIDS by gender ........ 48
  2.7.2 Awareness and knowledge about HIV/AIDS by morbidity status .................................................................................. 49
  2.7.3 Awareness and knowledge about HIV/AIDS by economic status .................................................................................. 50
2.8 Summary and conclusions .............................................................. 51

Pathways of Treatment Seeking Process and Factors affecting the Delay in Treatment ................................................................. 53-79

Chapter 3

3.1 Introduction ............................................................................ 53
3.2 Number of moves for treatment of tuberculosis ....................... 53
  3.2.1 Number of moves for treatment by selected characteristics... 54
  3.2.2 Type of sources selected for treatment by number of moves .................................................................................. 56
  3.2.3 Factors associated with the number of moves .................... 57
3.3 Chosen pathways of treatment by tuberculosis patients .......... 59
  3.3.1 Chosen pathways by gender ................................................. 59
  3.3.2 Chosen pathways by morbidity status ................................. 60
  3.3.3 Chosen pathways by economic status ................................. 61
  3.3.4 Chosen pathways by education ........................................... 62
3.4 Chosen pathways and type of delay in treatment ...................... 64
3.5 Patient delay in seeking treatment by socioeconomic characteristics ................................................................................ 65
### Chapter 3

3.5.1 Patient delay in seeking treatment by gender.......................... 65  
3.5.2 Patient delay in seeking treatment by morbidity status.............. 66  
3.6 Health system delays in reaching DOTS by socioeconomic characteristics .................................................................................. 68  
3.6.1 Health system delays in reaching DOTS by gender..................... 68  
3.6.2 Health system delays in reaching DOTS by morbidity status ...... 70  
3.7 Factors associated with delay in initiation of treatment............... 72  
3.7.1 Factors associated with delay in initiation of treatment among males .................................................................................................. 72  
3.7.2 Factors associated with delay in initiation of treatment among females .............................................................................................. 74  
3.8 Factors associated with health system delay in initiation of treatment ............................................................................................................. 76  
3.9 Summary and conclusions .............................................................. 78  

### Chapter 4

Consequences of Treatment Seeking Pathways on Health

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1</td>
<td>Introduction</td>
<td>80</td>
</tr>
<tr>
<td>4.2</td>
<td>Health outcome by individual characteristics of patient</td>
<td>81</td>
</tr>
<tr>
<td>4.3</td>
<td>Health outcome by disease characteristics of patient</td>
<td>83</td>
</tr>
<tr>
<td>4.4</td>
<td>Association of pathways of treatment with health outcome</td>
<td>84</td>
</tr>
<tr>
<td>4.5</td>
<td>Delay in treatment and health outcome</td>
<td>85</td>
</tr>
<tr>
<td>4.6</td>
<td>Adherence to treatment of tuberculosis</td>
<td>87</td>
</tr>
<tr>
<td>4.6.1</td>
<td>Reasons for non-adherence to treatment under DOTS</td>
<td>89</td>
</tr>
<tr>
<td>4.7</td>
<td>Success rate among subgroups of patients by background characteristics</td>
<td>91</td>
</tr>
<tr>
<td>4.7.1</td>
<td>Success rate by gender</td>
<td>91</td>
</tr>
<tr>
<td>4.7.2</td>
<td>Success rate by morbidity status</td>
<td>93</td>
</tr>
<tr>
<td>4.8</td>
<td>Determinants of successful health outcome</td>
<td>94</td>
</tr>
<tr>
<td>4.8.1</td>
<td>Determinants of successful health outcome by gender</td>
<td>96</td>
</tr>
<tr>
<td>4.9</td>
<td>Summary and conclusions</td>
<td>99</td>
</tr>
</tbody>
</table>

### Chapter 5

Economic Cost of Tuberculosis Treatment

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1</td>
<td>Introduction</td>
<td>101</td>
</tr>
<tr>
<td>5.2</td>
<td>Type of cost by hospitalization status</td>
<td>101</td>
</tr>
<tr>
<td>5.3</td>
<td>Type of cost of treatment by background characteristics</td>
<td>103</td>
</tr>
<tr>
<td>5.3.1</td>
<td>Direct cost of treatment for non-hospitalized patients</td>
<td>103</td>
</tr>
<tr>
<td>5.3.2</td>
<td>Indirect cost of treatment for non-hospitalized patients</td>
<td>106</td>
</tr>
<tr>
<td>5.3.3</td>
<td>Direct and indirect cost of treatment for hospitalized cases</td>
<td>108</td>
</tr>
<tr>
<td>5.4</td>
<td>Cost incurred during pathways of tuberculosis treatment</td>
<td>110</td>
</tr>
<tr>
<td>5.4.1</td>
<td>Direct cost and indirect cost incurred during pathways of treatment</td>
<td>110</td>
</tr>
<tr>
<td>5.4.2</td>
<td>Direct cost and indirect cost incurred during pathways of treatment among gender</td>
<td>111</td>
</tr>
</tbody>
</table>
5.4.3 Direct cost and indirect cost incurred during pathways of treatment among both the morbid groups......................... 112
5.4.4 Direct cost and indirect cost incurred during pathways of treatment among economic classes.......................... 113
5.5 Duration of treatment by pathways........................................... 114
5.5.1 Total duration of treatment for pathways followed among subgroups of patients by hospitalization status........ 115
5.6 Delay in treatment and associated type of cost .................. 117
5.6.1 Type of delay by direct cost of treatment ...................... 117
5.6.2 Type of delay by indirect cost of treatment ................ 119
5.7 Out-of-pocket treatment expenditure of tuberculosis patients... 121
5.7.1 Out-of-pocket treatment expenditure by selected characteristics.............................................................................. 121
5.7.2 Out-of-pocket treatment expenditure by number of moves of treatment................................................................. 122
5.8 Out-of-pocket expenditure by pathways ................................... 123
5.9 Factors leading to impoverishment among households of TB patients................................................................................ 124
5.10 Summary and conclusions ......................................................... 126

**Discrimination Faced by People Suffering from Tuberculosis**

Chapter 6 Tuberculosis .................................................................................. 128-152

6.1 Introduction ................................................................................................. 128
6.2 Disclosure of tuberculosis status ............................................................... 129
   6.2.1 Disclosure among TB-HIV co-morbid cases............................. 130
6.3 Discrimination faced at different settings by background characteristics.................................................................................. 130
   6.3.1 Family level discrimination faced by tuberculosis patients... 131
   6.3.2 Community level discrimination faced by tuberculosis patients...................................................................................... 132
   6.3.3 Health System discrimination faced by tuberculosis patients......................................................................................... 132
6.4 Types of discrimination faced by tuberculosis patients..................... 134
   6.4.1 Self-imposed discrimination faced by TB patients .............. 134
   6.4.2 Perceived discrimination faced by TB patients .................. 135
   6.4.3 Enacted discrimination faced by TB patients ..................... 135
6.5 Common forms of discrimination faced by TB patients .................. 137
6.6 Type of discrimination faced and delay in treatment......................... 138
6.7 Types of discrimination and number of moves made for treatment of tuberculosis ......................................................... 139
6.8 Types of discrimination faced and treatment outcome .................... 140
6.9 Number of discrimination faced by tuberculosis patients............. 141
   6.9.1 Number of family level discrimination faced among subgroups .................................................................................. 141
   6.9.2 Number of community level discrimination faced among... 142
6.9.3 Number of discrimination faced by selected characteristics ................................................................. 143
6.10 Factors affecting number of discrimination faced by tuberculosis patients .................................................. 145
6.10.1 Factors affecting number of discrimination faced among male .............................................................. 147
6.10.2 Factors affecting number of discrimination among female ...................................................................... 149
6.11 Summary and conclusions .......................................................................................................................... 151

Chapter 7 Summary, Conclusions and Policy implications of the Study .............................................................. 153-169
7.1 Introduction .................................................................................................................................................. 153
7.2 Summary of the results ............................................................................................................................... 155
  7.2.1 Profile, awareness and knowledge of TB and HIV ................................................................................. 155
  7.2.2 Pathways of treatment seeking process and factors affecting the delay in treatment ......................... 157
  7.2.3 Consequences of treatment seeking pathways on health outcome ....................................................... 158
  7.2.4 Economic cost of tuberculosis treatment .............................................................................................. 160
  7.2.5 Discrimination faced by people suffering from tuberculosis .................................................................. 163
7.3 Conclusions .................................................................................................................................................. 166
7.4 Policy implications ...................................................................................................................................... 168
7.5 Limitations of the study .............................................................................................................................. 169
7.6 Scope for future research ............................................................................................................................ 169

References ......................................................................................................................................................... 170-180
Appendices ......................................................................................................................................................... 181-206
  A.1 Variables for construction of wealth index using PCA ............................................................................. 181
  A.2 List of items used in construction of discrimination index ...................................................................... 181
  A.3 Interview schedule .................................................................................................................................. 182
Annexure ............................................................................................................................................................ 207-213