BEYOND THE HOSPITAL BED: STUDIES OF POST-DISCHARGE SOCIOECONOMIC AND QUALITY OF LIFE OUTCOMES IN TRAUMA PATIENTS IN URBAN INDIA

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BEYOND THE HOSPITAL BED: STUDIES OF POST-DISCHARGE SOCIOECONOMIC AND QUALITY OF LIFE OUTCOMES IN TRAUMA PATIENTS IN URBAN INDIA
THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

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The thesis will be defended in public at Inghesalen, Widerströmska Huset, Karolinska Institutet, Stockholm, Thursday the 12th of May 2022, at 08:00h

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To Papa George and Mummy Rachel, the first persons who pushed me to look beyond myself and sowed the seed of this journey in me.
There is no ghost so difficult to lay as the ghost of an injury.

-Alexander Smith, *Alfred Hagart's Household*
POPULAR SCIENCE SUMMARY OF THE THESIS

Globally, more people die every year due to trauma or injuries than due to HIV/AIDS, tuberculosis, malaria, and even the COVID-19 pandemic combined. Advances in medicine have led to more and more people surviving traffic injuries. Trauma may result in temporary or permanent disability. It may require more treatment and hospital visits after discharge. It can affect where and how you can travel, which washrooms you can use, whom you can interact with, which events you can participate in, and which jobs you can take up.

The different types of additional medical treatments after discharge and trying to adjust in the altered life can be very expensive. It could empty the life savings of some families and push others into debt. These social and economic outcomes can deteriorate the quality of life of those affected with trauma. Your age, sex, and background can influence which of these problems affects you more than others. Moreover, these issues may last for some time, a long time, or, in some cases, an entire lifetime.

Most trauma occurs in low- and middle-income countries such as India. Yet, we do not know much about what happens to trauma patients once they leave the hospital in these countries. How long does it take for them to get back to work? How much money do they end up spending? How does it affect their families? We do not know how these outcomes affect them and their families. Studying more about these outcomes can provide a better understanding of the challenges faced by trauma patients and enable healthcare providers, hospital administrators, and law-makers to design policies and programs to help patients to cope with the consequences of trauma in countries such as India.

This study is an attempt to know more about the lives of trauma patients after their discharge from hospital in urban India. It reviews what is currently known about what happens to trauma patients across the world after they leave hospital. It explores the different socioeconomic issues they face and how the quality of their lives changes after the trauma in urban India. The study also attempts to find out whether prediction models can be developed to study these outcomes in trauma patients. It finally aims to find out how age and sex might influence the quality of life in trauma patients after discharge across cities in India.

We found that, across the world, even after a year, one in three patients does not get back to work and the quality of their lives still does not reach the level it was prior to the trauma. In urban India, trauma patients after discharge struggled to receive the treatments they required and faced financial burdens. Depending on your age and sex, you experience these challenges differently. Support and care from family, neighbors, and the society is important to continue recovery after being discharged. We learned that we can develop models for specific groups of trauma patients in different places to predict their outcomes. Pain, not being able to carry out their usual activities, and psychological problems are the main problems affecting the quality of life of trauma patients. Older adults and females tend to have the worst quality of life after the trauma.
ABSTRACT

Background: Trauma contributes to one-tenth of the global morbidity, with low- and middle-income countries (LMICs) bearing a disproportionate burden. It is the biggest contributor of morbidity among young adults, and there is scope for substantial work to be done to address this global public health issue. Trauma morbidity has long-term social and economic consequences that extend beyond discharge from hospital, affecting the quality of life of trauma survivors though their recovery. Patient and trauma characteristics influence these outcomes and the healthcare system can play a role in improving these outcomes. However, most of the evidence on these post-discharge outcomes comes from high-income countries. Consequently, they remain poorly understood in LMIC settings. Building on evidence from these settings can help identify specific needs of post-discharge trauma patients and develop policies and practices to strengthen the existing healthcare system to meet the recovery needs of patients in LMICs.

Aim: The aim of this thesis was to study post-discharge outcomes and factors associated with such outcomes in adult trauma patients in urban areas in India, which contributes more than 20% of the global trauma morbidity.

Methods: Paper I assessed the current evidence on post-discharge socioeconomic and QOL outcomes in trauma patients by conducting a systematic review and meta-analysis of peer-reviewed scientific papers on key post-discharge socioeconomic and QOL outcomes among trauma patients. Paper II explored how post-discharge socioeconomic and QOL outcomes were experienced by trauma patients in urban India through thematic analysis of semi-structured interviews, in the city of Mumbai, India. Paper III developed and validated local trauma severity models to predict trauma outcomes in the context of India using machine learning techniques using data from a multi-center cohort of trauma patients. Paper IV determined the interaction of age and sex with post-discharge QOL outcomes in adult trauma patients from four cities in urban India.

Results: The findings indicate that even a year after the trauma, one-third of participants had not returned to work and QOL was less than the pre-trauma and general population levels [I]. Trauma patients in urban India experienced post-discharge socioeconomic and QOL outcomes as incomplete, expensive, and inter-social recovery and social support was an important factor in reducing the effect of the outcomes [II]. Paper III, shows that locally developed models have better discrimination and calibration in predicting trauma mortality than the widely used global gold-standard, Trauma Injury Severity Score (TRISS). Older
adults, particularly females, have the lowest health status, while middle-aged females have the highest odds of having problems across different QOL domains. The inability to perform usual activities, the persistence of pain, and the presence of psychological morbidity were the main drivers of QOL among urban Indian trauma patients [IV].

**Conclusions:** Socioeconomic and quality-of-life outcomes continue to remain affected up to a year after discharge in trauma patients. Post-discharge socioeconomic and quality-of-life outcomes are unmet, costly to improve, and strongly shaped by social roles among trauma patients in urban India. Local models are better suited for prediction of outcomes in academic research and trauma quality improvement programs. Age and sex are associated with post-discharge QOL among trauma patients in urban India.

**Key words:** trauma, quality-of-life, socioeconomic, age, sex, India

II. David SD, Roy N, Stålsby Lundborg C, Gerdin Wärnberg M, Solomon H. “Coming home does not mean that the injury has gone”—Exploring the lived experience of socioeconomic and quality of life outcomes in post-discharge trauma patients in urban India. *Global Public Health*. 2022 Feb 6;1-21 [DOI: https://doi.org/10.1080/17441692.2022.2036217]

III. David SD, Roy N, Solomon H, Stålsby Lundborg C, Gerdin Wärnberg M. Development and validation of a local trauma severity score for adult trauma patients in urban India. [Manuscript]

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<table>
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<th>Description</th>
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<tbody>
<tr>
<td>AIS</td>
<td>Abbreviated Injury Score</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence Interval (at 95%)</td>
</tr>
<tr>
<td>DALYs</td>
<td>Disability-adjusted life-years</td>
</tr>
<tr>
<td>ED</td>
<td>Emergency Department</td>
</tr>
<tr>
<td>EQ5D</td>
<td>EuroQoL-5 Dimensions (Quality of life measure)</td>
</tr>
<tr>
<td>HICs</td>
<td>High-income countries</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>ICI</td>
<td>Integrated Calibration Index</td>
</tr>
<tr>
<td>ISS</td>
<td>Injury Severity Scale</td>
</tr>
<tr>
<td>LMICs</td>
<td>Low- and middle-income countries</td>
</tr>
<tr>
<td>OR</td>
<td>Odds ratio</td>
</tr>
<tr>
<td>PRISMA</td>
<td>Preferred Reporting Items for Systematic Reviews and Meta-analyses</td>
</tr>
<tr>
<td>QOL</td>
<td>Quality-of-life</td>
</tr>
<tr>
<td>RTW</td>
<td>return to work</td>
</tr>
<tr>
<td>SDG</td>
<td>Sustainable Development Goals</td>
</tr>
<tr>
<td>TAFT</td>
<td>Trauma Audit Filters Trial (Project)</td>
</tr>
<tr>
<td>TITCO</td>
<td>Towards Improved Trauma Outcomes-India (Research Consortium)</td>
</tr>
<tr>
<td>TRISS</td>
<td>Trauma and Injury Severity Score</td>
</tr>
<tr>
<td>TTRIS</td>
<td>Trauma Triage Study (Project)</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>YLL</td>
<td>Years of life lost</td>
</tr>
<tr>
<td><strong>DEFINITIONS</strong></td>
<td></td>
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<tr>
<td>------------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Quality of Life</strong></td>
<td>The perceived physical, mental, and social well-being of a person</td>
</tr>
<tr>
<td><strong>Return to work</strong></td>
<td>Being able to return to any form of paid employment after trauma</td>
</tr>
<tr>
<td><strong>Socioeconomic</strong></td>
<td>Relating to or concerned with the interaction of social and economic factors</td>
</tr>
<tr>
<td><strong>Trauma</strong></td>
<td>Wound or physical injuries caused by an external force</td>
</tr>
</tbody>
</table>
1 PREFACE

In his preface, Martin explained that ‘there are no accidents’ as everything can be predicted. As an Indian, I have been programmed to believe that everything is destined. But I don’t believe in destiny. I did not set out to work, let alone do my doctoral thesis, in post-discharge outcomes in trauma patients. I have neither seen nor had anyone among my family or friends injured.

A decade ago, as an undergrad in Life Sciences and Biochemistry, I would spend hours in the Humanities Section of the St. Xavier’s College library. I liked to read everything. I remember reading about the evolution of religious identities in India as a result of colonial British bookkeeping, the impact of the Napoleonic wars on the rise of fascism in Europe, and the role of climate change in the collapse of the Mayan civilization in Mesoamerica. I was fascinated then, and am still, by the way different things interact with each other to create outcomes. This led me away from “pure sciences” to seek spaces that combined different disciplines.

During my post-graduation in Disaster Management at the Tata Institute of Social Sciences, every student got to pick two specializations. In keeping with my fascination for different disciplines, I chose four specializations (only because I could not enroll in all five specializations, it being physically impossible for a student to sit for all classes due to their parallel nature). When I finally decided to work in public health, thanks to my professor Dr. Roy, I worked on pollution, asbestosis, conflict, gender-based violence, health inequities, antibiotic resistance, and complex disasters. Both in the field collecting data and, on a computer, writing up the findings. I brushed over many areas but never deep-dived into any. Everything intrigued me, but nothing anchored me.

In the midst of this, I met Martin. He was as focused as I was scattered, as composed as I was talkative, as disciplined as I was disorganized.

We were leading a group of student volunteers as part of a humanitarian response in a conflict zone in north-eastern India. We annoyed each other and I bored him. But in the conflict, we developed a close friendship. His focus, composure, and discipline rubbed off on me—very superficially. But just enough for him to let me be an observer of the trauma projects he was working on. Within my cluttered “areas of interest” in public health, I slowly got drawn to the structure within the unpredictability of trauma outcomes.

One evening in 2016, over dinner in the middle of a busy bazaar in Mumbai, Martin asked me why I kept putting off my doctoral studies. I mumbled about being unable to pick a subject, waiting for the perfect topic and the ideal university. Martin told me that the topic was not important. Rather, it was the learning the process. Being able to independently conduct research using robust methodologies, subject to critical review, and with scientific rigor, is what mattered. It did not make a difference whether it was trauma or asbestosis. I could pick one for my doctoral studies and develop the skills to be able to work on the other.
In the next two years, I was able crystallize my interests, read up on literature, and discuss my ideas. I finally arrived at my topic as it was an opportunity to interact with people and look beyond the clinical aspects of trauma. During my enrollment in 2018, and over the course of my doctoral work with post-discharge trauma patients, I began to see the links emerge between my doctoral topic—which I thought was completely random—and my life.

One morning, when I was around two years old, my father woke up with hemiplegia. At the hospital he was diagnosed with Guillain-Barre Syndrome. The doctors told my father that the prognosis would be spending a long time, maybe a lifetime, in a wheelchair. It seemed unimaginable for him as a footballer, a kayaker, and a chef. He told his wife that he could not bear to live a life bound to a chair, with limited social interactions, and a burden to the family. He passed away three days later. My father was 36.

14 years later, my grandfather was taken ill. He became bed-ridden and had to be fed, cleaned, and bathed. It was painful to see a tough, decorated ex-naval commander reduced to an invalid in bed. He lived with his son and his family. Another son who had retired was there to nurse him. His daughter and daughters-in-law took turns caring for him. His grandchildren regularly hopped on his water bed, trying to cheer him up saying, “Command your warship, Sir!” He would smile in his delirious state. He died peacefully a few weeks later. My grandfather was 80.

Another 14 years later, my mother was diagnosed with pituitary adenoma. She was a single parent of a single child. She was just a week away from her retirement. She had more than enough savings to undergo the surgery. She didn’t have to return to work; rather settle into to a comfortable retirement. Her son had a job that allowed him to take time-off to look after her. Post-discharge, her nephew and his wife—both clinicians—asked her to live with them for a few weeks so that they could monitor her health. Her friends and family dropped in to look after her. At times it was depressing to see an independent, germophobic woman require help to bathe or clean herself. She recovered over a few months. My mother was 60.

I could see that I was studying concepts and phenomena in my research and through my participants that seemed to mirror my own life. The stories and challenges appeared to parallel with my own experiences. The doctoral topic did not seem very random anymore. Now, I can say that I am more interested, more focused, and slightly more disciplined to work with patient outcomes and experiences within trauma than any other subject. I look forward to being able to do research in this field in the coming years. I still do not know whether my doctoral topic was an accident or destiny.

Or both.

Or neither.
2 INTRODUCTION

Trauma is the Greek word for wound—specifically physical injuries—and is usually used to describe an injury to tissues caused by an external force (1). As the word is also used to describe an emotional or psychological state or condition, in order to distinguish the two, the term physical trauma is also used (2). Sometimes both trauma and injury are used interchangeably to describe the physiological harm caused by external causes (3). Trauma is described by the mechanism of injury, for example, transport injuries, falls, self-harm, assaults, and burns; the body part injured, as in spinal cord injuries or traumatic brain injuries; or the nature of the trauma: penetrating like a bullet injury and blunt like a fracture after a fall.

2.1 Trauma as a global public health issue

Every day across the world, more than 12,000 people die because of trauma, accounting for one in every twelve deaths (4). Trauma is estimated to outnumber the deaths due to infectious diseases including HIV/AIDS, TB, malaria, and the current Covid-19 pandemic combined (5). The most common mechanism of injury is transport injuries, followed by self-harm and falls, with certain mechanisms, like falls and violence-related injuries, steadily rising over the years (6,7). Though trauma is prevalent in every country, it is distributed disproportionately in low- and middle-income countries (LMICs) which bear almost 90% of the trauma mortality, a significant proportion of which is preventable (8,9). Improvements in healthcare services and socioeconomic development have reduced trauma mortality and the focus has moved to the survivors (7,10–12).

For every person who dies because of trauma, there is a large number of persons who survive. It is estimated that for every one trauma death there are 85 non-fatal trauma survivors in high-income countries (HICs), while in LMICs this is as high as 476 (13–15). Nearly one-tenth of the global disability-adjusted life-years (DALYs) is because of trauma (16). Again, transport injuries account for nearly 30% of the global trauma DALYs, followed by falls (15%), and self-harm (13%) (16). Trauma morbidity for certain mechanisms such as falls and conflicts has been seen to be growing over time. Trauma is the main cause of DALYs among 25–49-year-olds and is among the top-ten causes of DALYs in the 50 and above age group (16). Overall, trauma affects more males than females. Globally, trauma also accounts for nearly 11% of the years of life lost (YLLs) across all disease conditions globally (16). In the last three decades (1990-2017), the number of years lived with disability due to trauma has increased by more than fifty percent (17). The burden of trauma morbidity is again disproportionately borne by LMICs, which have nearly 86% higher DALYs compared with HICs (18). Therefore, addressing the burden of trauma morbidity, especially in LMICs, is an important global public health agenda.

The Sustainable Development Goals (SDGs), which aim to achieve holistic human development for all by setting goals for countries to meet, has recognized the global burden of trauma. One of its targets was to reduce the burden of road traffic injuries by half by the year 2020, as part of SDG 3 (Ensure healthy live and promote well-being for all at all ages)
Addressing the trauma morbidity burden is also important for meeting SDG 11 (Make cities and human settlements inclusive, safe, resilient, and sustainable) and SDG 16 (Promote peaceful and inclusive societies for sustainable development; promote access to justice for all; and build effective, accountable, and inclusive institutions at all levels). However, progress on the matter has been slow. This led to the Stockholm Declaration, 2020, which called upon all countries to work to halve the trauma burden by 2030 (20). Thus, trauma morbidity continues to remain a crucial global public health issue.

2.2 Post-discharge outcomes of trauma

Trauma can damage the body by affecting organ systems and disrupting physiological functioning; it may also lead to temporary or permanent disabilities (21,22). In addition, it results in psychological stress and affects the mental well-being of trauma patients after discharge (23,24). It also has social and economic consequences beyond the discharge affecting the lives of survivors and their families. Physical challenges after trauma can restrict community and social participation (25). Limited accessibility, social stigma, and lack of support were identified by post-discharge trauma patients as major obstacles in community participation (26–28). Trauma can lead to loss of autonomy and the inability to function as before (29). This necessitates increased social support to be able to return to the pre-injury way of life or adjust to the altered way of life (30). This can put pressure on support systems like family and friends, and affect relationships (31–33). It can also lead to loss of pre-trauma roles and being forced to accept restricted duties as spouses and parents (34,35).

Trauma also puts an economic burden on post-discharge trauma patients. Missing work or loss of work is a common challenge after trauma recovery. Some studies report that between 50–60% of patients are able to return to work (RTW) after suffering trauma, but for severe trauma it can be as low as 30% (36–38). Trauma also results in direct costs including expenses towards follow-up care, rehabilitation services, medicines, and transportation costs, as well as other costs such as the cost of caregiving and loss of incomes (39,40). Without adequate compensation, insurance, or other buffers, these costs can push households into debt and poverty (41–43). These socioeconomic outcomes affect the quality of life (QOL)—the perception of wellbeing across physical, mental and social domains of health—in trauma patients (44). Social participation, good relationships, and RTW were strongly associated with better QOL (45–47). Socioeconomic outcomes like community integration, social relationships, RTW also affect the psychological well-being of trauma patients after their discharge (48–50).

The severity of the trauma affects the range and length of physical problems and consequently post-discharge socioeconomic and QOL outcomes. Sociodemographic factors also influence these outcomes. Some studies report that females tend to report more psychological stress, find it difficult to return to work, and have lower QOL (51,52); other studies indicate that males perform worse (53,54). The instances for poorer outcomes for males could be linked with males having more severe injuries than their female counterparts (52). Older adults, in general, have lower QOL outcomes due to co-morbidities, limited
functioning related to age, and lack of support networks (55–57). Older females, in particular, report poorer outcomes than older males (58,59). Along with sex and age, lower socioeconomic status and education have been linked with poor post-discharge QOL outcomes in trauma patients (60,61). Interaction of sociodemographic outcomes has been shown to determine the trajectory and experience of different post-discharge outcomes in trauma patients (62).

### 2.3 Post-discharge recovery

Recovery is viewed by trauma patients as the process of getting back to normal or a new way of living after the trauma (63,64). As described above, trauma has consequences that can extend beyond the hospital. Therefore, the recovery process of returning back to normal can be long. Some physical conditions like pain or disability may become chronic in nature, psychological morbidity can continue for a long term, and socioeconomic and QOL outcomes can remain poor for as long as 3–7 years (65–67). Most trauma patients are discharged when their immediate physiological needs have been managed. As a result, the rest of their recovery process gets transferred with them to their homes. The need to view recovery in a holistic way, encompassing psychological, social, and economic aspects to reintegrate the trauma patient as much as possible to her pre-injury status is important (68). There are frameworks that attempt to describe the process of recovery of trauma patients.

In 2001, the WHO developed the International Classification of Functioning, Disability and Health (ICF), a framework for understanding at functioning after a health condition (69). The ICF views recovery through a “biophysiosocial model” where a health condition, like trauma, interacts with the contextual factors such as the environment and personal attributes, leading to different patient outcomes (69). The model shows that the health condition interacts with body function and structure, participation (involvement in life situations), and contextual factors (physical, social, and attitudinal environment, systems, policies, etc.) to determine a person’s ability to perform any activity be it being able to walk or returning to work (Figure 2.1). Thus, the recovery process is determined by physiological, personal, and environmental factors.
Halcomb and Davidson applied the illness trajectory framework developed by Corbin and Strauss on trauma recovery (Figure 2.2) (70). They viewed post-discharge recovery of trauma patients as a trajectory starting with an acute phase that requires medical interventions to treat injuries, followed by a stable phase that may require some or no healthcare interventions. Subsequently, recovery may deteriorate to an unstable phase due to emerging complications or challenges due to the consequences of the trauma. On addressing these challenges, the recovery enters the stable phase. If not, the condition worsens. This model recognizes that recovery in trauma patients can be long and non-linear. It also recognizes the role played by the healthcare system in recovery.

Figure 2.2 Illness Trajectory Framework Applied to Trauma Patients (Halcomb and Davidson, 2005) (70)
Richmond and Aitken tried to incorporate the nature of healthcare interventions and the role of the environment—family, surroundings, availability of healthcare services, etc.—in the recovery process and developed the Trauma Outcomes Model (Figure 2.3) (71). It stresses that healthcare interventions during the different phases after the trauma are connected. Recovery is best achieved by integrating them while keeping in mind the need of the trauma patient and her environment. It views trauma as a health condition influenced by a person’s social, economic, cultural, and physical environments. These environments also influence the type of trauma care that the healthcare system can provide and the safety nets that patients have in order to cushion the consequences of the trauma. Therefore, the focus of the healthcare system is to meet the different needs of trauma patients and reduce not just trauma mortality and morbidity, but enhance all aspects of their recovery.

![Figure 2.3 Trauma Outcomes Model (Richmond and Aitken, 2011) (71).](image)

Thus, recovery for trauma patients can be long and non-linear and may be influenced by different environmental factors. An integrated healthcare approach that is able to cater to the different needs of trauma patients is better suited for good recovery.

### 2.4 Measuring post-discharge outcomes

Trauma has a range of physiological, socioeconomic, and QOL of outcomes, and measuring them becomes important in order to study progress or deterioration, for comparison between patients, and to audit the efficacy of interventions. Scoring injuries to measure their severity
is an important part of the clinical management of trauma patients in the hospital, and it is essential for comparing different patients across settings in a standardized way and useful for predicting trauma outcomes in research (72). Trauma severity is measured based on the anatomical nature of trauma, that is the body part injured or the number of injuries; or the effect of the trauma on physiological functions like systolic blood pressure, respiratory rate, and verbal responses; or a combination of both anatomical and physiological variables. An ideal trauma severity score should be objective, replicable in different settings, less resource-intensive, and able to be revised over time (73). Therefore, using a trauma severity score best suited to a specific context is important. Some of the most commonly used scores to measure trauma severity are given in Table 2.1.

Table 2.1 Common Trauma Severity Scores

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td><strong>Glasgow Coma Scale (GCS)</strong> (74)</td>
<td>This is a physiological score that measures motor response, verbal response, and eye opening to stimuli, and combines them into a single score.</td>
</tr>
<tr>
<td><strong>Abbreviated Injury Score (AIS)</strong> (75)</td>
<td>This is an anatomical score that grades injuries according to the body region affected.</td>
</tr>
<tr>
<td><strong>Revised Trauma Score (RTS)</strong> (76)</td>
<td>This is a physiological score that is based on GCS, respiratory rate, and systolic blood pressure in trauma patients.</td>
</tr>
<tr>
<td><strong>Injury Severity Scale (ISS)</strong> (77)</td>
<td>This anatomical score builds on the AIS score by assessing overall severity of multiple injuries by selecting one injury per body region.</td>
</tr>
<tr>
<td><strong>New Injury Severity Scale (NISS)</strong> (78)</td>
<td>This is a revised version of the ISS, allowing the inclusion of three injuries per body region.</td>
</tr>
<tr>
<td><strong>Trauma and Injury Severity Score (TRISS)</strong> (79)</td>
<td>This is a composite score using both the anatomical ISS and the physiological RTS, along with age and whether the trauma is a penetrating or blunt injury. It is one of the most widely used scores in the world.</td>
</tr>
</tbody>
</table>

In terms of post-discharge outcomes, there is great variability in the tools and scores used to measure these outcomes: the same tools are used to measure different things, and different tools are used to measure the same thing (80). Additionally, most studies on post-discharge outcomes focus on specific types of trauma, such as pelvic injuries, spinal cord injuries, burns or road traffic injuries (81). Some widely studied post-discharge socioeconomic and QOL outcomes identified through a scoping review conducted as part of this thesis are given in Table 2.2.
Table 2.2. Widely Studied Socioeconomic and Quality of Life Outcomes and Measures

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Tools</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Life</td>
<td>Short-Form 36/12/6 (SF-36/12/6) (82)</td>
</tr>
<tr>
<td></td>
<td>Euro Quality of Life (EuroQoL: EQ-6D/5D/3D) (83)</td>
</tr>
<tr>
<td></td>
<td>World Health Organization Quality of Life Assessment (WHOQOL-BREF) (84)</td>
</tr>
<tr>
<td></td>
<td>Quality of Life after Brain Injury (QOLIBRI) (85)</td>
</tr>
<tr>
<td></td>
<td>Burn Specific Health Scale-Brief (BSHS-B) (86)</td>
</tr>
<tr>
<td>Return to Work</td>
<td>Back to any work (Yes/No)</td>
</tr>
<tr>
<td></td>
<td>Sick leave/Time off</td>
</tr>
<tr>
<td></td>
<td>Unemployment benefits</td>
</tr>
<tr>
<td></td>
<td>Staying at work for at least a month</td>
</tr>
<tr>
<td></td>
<td>Activities Component of EQ-5D (83)</td>
</tr>
<tr>
<td>Social Support</td>
<td>Support from family, friends, and neighbors (Yes/No)</td>
</tr>
<tr>
<td></td>
<td>Multidimensional Scale of Perceived Social Support (MSPSS) (87)</td>
</tr>
<tr>
<td></td>
<td>Social Support Questionnaire (SSQ) (88)</td>
</tr>
<tr>
<td></td>
<td>Social Provision Scale (SPS-12) (89)</td>
</tr>
<tr>
<td></td>
<td>Interpersonal Support Evaluation List (ISEL) (90)</td>
</tr>
<tr>
<td>Participation</td>
<td>Craig Hospital Assessment and Reporting Technique (CHART) (91)</td>
</tr>
<tr>
<td></td>
<td>Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) (92)</td>
</tr>
<tr>
<td></td>
<td>International Classification of Functioning, Disability and Health Checklist (ICF) (93)</td>
</tr>
<tr>
<td></td>
<td>Community Integration Questionnaire (CIQ) (94)</td>
</tr>
<tr>
<td></td>
<td>WHO Disability Assessment Schedule (WHODAS II) (95)</td>
</tr>
<tr>
<td>Community Integration</td>
<td>Community Integration Questionnaire (CIQ) (94)</td>
</tr>
<tr>
<td></td>
<td>Community Integration Measure (CIM) (96)</td>
</tr>
<tr>
<td></td>
<td>Craig Handicap Assessment and Reporting Technique (CHART) (91)</td>
</tr>
<tr>
<td></td>
<td>The Sydney Psychosocial Reintegration Scale (SPRS) (97)</td>
</tr>
</tbody>
</table>

Adapted from (David et al, 2021) (80).

Measuring patient outcomes enables healthcare providers and health researchers to understand the patient’s assessment of her needs and health status. Despite being objective and comprehensive, no single score or measurement tool can fully capture the patient’s experience. Different outcomes may mean different things to different patients at different points of time and the weightage assigned to domains within the outcomes can also vary with time or the patient’s environment. For instance, participation can be viewed differently: for some it may mean inter-personal interactions and for others it may mean involvement in community or social events; some may consider pain to be more pertinent for their health status than being able to move around without help; and tolerance to pain may be influenced by social or cultural factors. Therefore, it is important to compliment measurable numeric scores or tools with qualitative exploration of these outcomes through narratives of patient experience of these outcomes (98). This will provide more insights on how these outcomes are encountered by patients and better inform practice and policy to address them.
2.5 Role of the healthcare system in trauma morbidity

As pointed out in earlier sections, the healthcare system can play a major role in trauma care. The management of trauma begins with pre-hospital care, acute care at the hospital, and continued care throughout the recovery process (99). From a trauma morbidity perspective, rehabilitation services are crucial in the process of recovery (100,101). Providing adequate follow-up care for trauma patients after discharge is important to identify and screen for different physical and psychological conditions and provide treatment or referrals (102). Different types of traumas would require different kinds of post-discharge rehabilitation services. Moreover, this requires an integrated approach involving different departments within the healthcare system, as well as public welfare programs, the employment sector, etc. (103,104). An organized and integrated trauma care providing a continuum of care is essential to improve post-discharge outcomes and facilitate a trauma patient’s integration into her pre-trauma life.

However, gaps in the provision of such care for trauma patients continue to exist. Most patients tend to get discharged after the acute physiological effects of the trauma are addressed, without assessment or meeting of their rehabilitation needs (70). An integrated continuum of care along with rehabilitation is neither available nor accessible, nor is it affordable for trauma patients in most LMICs (105–108). Even in organized healthcare systems in HICs, such care tends to suffer from being poorly coordinated, inadequately resourced, expensive, and unable to fully meet all the needs of trauma patients (109–111). Consequently, this burden of care shifts to the patients and their families. If they are unable to meet them, it worsens their post-discharge health as well as socioeconomic and QOL outcomes.

Recognizing the role played by rehabilitation care and the unmet needs of such care among trauma patients, the WHO initiated the “Rehabilitation 2030” (112). It calls for the healthcare system to have an integrated approach to treating trauma and includes rehabilitation. It proposes the expansion and allocation of resources, building capacity, and collecting evidence on rehabilitation care in all settings, especially in LMICs. It pushes to document and develop strategies and prioritize rehabilitation as part of improving trauma care. Recently, the use of mobile technologies for teleconsultations, monitoring trauma patients, and assessing their outcomes at different stages of trauma care is emerging as a novel strategy to improve care (113,114). However, there continue to exist barriers of accessibility, feasibility, useability, and costs, especially in LMICs. (115–117). Therefore, an organized and integrated healthcare system is important to mitigate the needs of and improve post-discharge socioeconomic and QOL outcomes in trauma patients.

2.6 Seeking care for trauma morbidity

Along with the availability of adequate affordable healthcare services, there can be different factors that influence the uptake of these services by trauma patients. There have been attempts to describe healthcare-seeking behavior among patients. Kleinman developed
explanatory models of illness to describe how healthcare-seeking behavior is not just determined by patients’ health needs (118). According to this model, along with the severity of the health condition, the patient’s own expectations of the treatment and her perceptions of her health condition determine her healthcare-seeking behavior. Research by Lane and Millar, showed that age, sex, and socioeconomic status also strongly influence how healthcare is sought (119). Anderson developed a behavioral model on accessing healthcare services, in which he explained that along with environmental factors and enabling socioeconomic factors, perceived change in health outcomes and satisfaction of care also shape healthcare-seeking behavior (Figure 2.4) (120).

![Figure 2.4 Health Behavior Model (Anderson 1995)](120).

In the context of post-discharge trauma patients, the factors outlined above have also been seen to influence healthcare-seeking behavior. Along with the cost of care, perceived severity of trauma, the lack of information, the inability to access transportation, the pressure of not missing work to seek healthcare, the behavior of healthcare providers, and poor quality of treatment have all been reported as factors affecting healthcare-seeking behaviors in trauma patients (121–123). Trauma patients have attributed seeking traditional healers to bypass these challenges with the formal healthcare systems (124,125). Keeping in mind these aspects of healthcare-seeking behavior can help in developing integrated healthcare services that are more acceptable and fit the needs and expectations of post-discharge trauma patients.

### 2.7 Trauma morbidity in India

Though 17% of the global population lives in India, the country accounts for 21% of the global trauma burden (126). In India, trauma accounts for more than one-tenth of the total deaths in the country, with road traffic injuries and self-harm among the top ten causes of overall mortality (127). The latest GBD statistics show that the morbidity burden of trauma has been steadily increasing in India, from 8% in 1990 to 11% of DALYs in 2019 (126). A 2017 report by the India State-Level Disease Burden Initiative (128) indicated that road
traffic injuries and self-harm were the main mechanisms of injury contributing to this burden growing by 65% and 30%, respectively (Figure 2.5). The report also highlighted that young adults, specifically males, account for most of the DALYs due to traffic injuries. The proportion of DALYs in India due to self-harm was almost twice as much as other countries at the same level of development (128).

![Figure 2.5 Contribution of Different Mechanisms of Injury to Disability Adjusted Life Years (DALYs) in India, 2019 (126)]

In 2020, there were 336,248 traffic injuries in India, more than two-fifths of which were due to two-wheelers (129). Traffic injuries are the biggest contributors of trauma morbidity in India. Almost one-third of the global trauma morbidity due to motorcyclist injuries and one-fourth of morbidity due to railway injuries are from India (126). More than 80% of the traffic injuries have been attributed to speeding and careless driving (129). Poor compliance with road safety rules, such as wearing helmets, using seatbelts, and not consuming intoxicants, have shown to be the other factors contributing to this burden in urban India (130–133). Additionally, lack of affordable and efficient public transport forces urban residents, especially those from lower socioeconomic groups living in the peripheries of urban areas, to use old, unmaintained vehicles and travel in overcrowded vehicles, which increases the risk of road accidents (134). Stricter enforcement of traffic rules, more awareness programs, and changes in attitudes towards road safety seem to be improving traffic accidents in recent years (135–138).

Cases of self-harm in India have been rising each year, with 2020 reporting a 10% increase from the previous year (129). India accounts for 30% of the global DALYs for self-harm, especially among females, which is 44% of the global burden (126). Government records show that more males than females committed suicide, yet females have a larger morbidity burden than males in India (129). Early marriage, intimate partner-based violence, socioeconomic vulnerability, and limited opportunities to deal with stress have been cited as reasons for the high burden of self-harm in females in India (139). It was only in 2017 that
suicide was decriminalized in India. This, along with the social stigma surrounding mental health, poor surveillance, and the lack of context-specific prevention or rehabilitation solutions, keeps the morbidity due to self-harm an unaddressed social and public health crisis in India (140).

India accounts for one-fourth of the global DALYs due to falls (126). Falls, which mainly affect older adults, as a mechanism of injury have been rising in India as a result of increased life expectancy (141). Older adults are susceptible to imbalances due to reduced physiological functioning. Within the limited research on falls in India, it is estimated around 30% of older adults in India likely experience falls in their lifetimes (142,143). Social isolation, limited access to resources, and restricted employment opportunities among older adults, females in particular, make them vulnerable to poor post-discharge outcomes in India (144).

Though India bears around 21% of the global DALYs due to burns, segregating it by sex, raises this to 30%, and again taking a younger female cohort into account raises it to 40% of the global burden (126). This shows how age and sex are strong determinants of burns in India. There is evidence of how burns patients in India are predominately composed of females who commit self-harm, are subjected to gender-based violence, and work around unsafe kitchen stoves (145–149). Given the complicated social, cultural, and psychological factors behind these types of burns, it would have a very strong bearing on post-discharge socioeconomic and QOL outcomes.

India’s share in the global morbidity burden due to interpersonal violence is less than 10%, with certain forms of violence like firearms-related, conflict, and police executions at 4%, 2%, and 2%, respectively (126). India’s share in the global DALYs due to sexual violence was around 13% among females and 17% among males [59]. However, the national household-level survey using a representative sample of households throughout India—the National Family Health Survey—reported that while there has been a fall in gender-based violence in India over the years, in 2019-20 around 30% of females still reported being subjected to different forms violence (150,151). Underreporting and poor documentation of gender-based and sexual violence has been observed in the urban Indian setting (152–154). On the other hand, sexual violence faced by males and sexual and gender minorities receives less attention, attracts limited legal recourse, and remains stigmatized in India (155–157).

In spite of the enormous burden of trauma morbidity in India, there has been little research on the post-discharge outcomes of trauma in urban India. Estimating the financial burden due to trauma has been one of the relatively better studied outcomes. Studies report 30-50% of households being pushed into catastrophic health expenditure, i.e., spending more than 10% of the total household expenditure to bear the consequences of trauma (158–160). There has also been research on the physiological morbidity in inter-personal violence, with respect to gender-based violence in urban India (161–164). But other long-term post-discharge outcomes have not been sufficiently studied in this context. Recently there have been studies that aim to address this gap by exploring outcomes like QOL after trauma (53,165,166).
Thus, there is a lot of scope for much more research into the range of post-discharge socioeconomic and QOL outcomes in urban India.

Available estimates do give insights into trauma morbidity in India, but the inability to capture the exact burden of trauma and its outcomes continues be an issue in the context of India, as with most LMICs. Most mechanisms of injury are considered to be medico-legal in nature. Hospitals and law enforcement agencies are the primary sites for collecting trauma data in India. Poor surveillance systems, underreporting, incomplete information, and limited resources—both human and financial—continue to plague the evidence on trauma morbidity in India (167–170). Though it would be a mammoth task, comprehensive standardized data, at least at local or regional levels, can help better understand the outcomes of trauma morbidity, as well as push for more resources and develop more efficient and targeted programs to address them in the context of India.

2.8 The Indian healthcare system

With a population of around 1.3 billion people, India is a lower middle-income country with a multiethnic, multilingual, and multireligious population (171). It has experienced differential human development across its regions, leading to wide variations in distribution of diseases and health conditions across the country (127). Life expectancy at birth is 68.6, though it varies widely between the Indian states: 65.7 years in Uttar Pradesh to 76.25 years in Kerala (128). It is estimated that India on the whole achieved epidemiological transition—the ratio of DALYs caused by communicable, maternal, neonatal and nutritional diseases to those caused by non-communicable diseases and injuries—in 2003. However, there is a wide disparity amongst Indian states with some achieving it as early as 1986 while others only in 2010. (127,128). Figure 2.6 gives the change in DALYs over time in India. India thus faces the joint burden of increasing rates of non-communicable diseases and injuries and the still large number of communicable diseases. A comparison of key indices of India and the world is provided in Table 2.3.

![Figure 2.6 Distribution of Disability Adjusted Life Years (DALYs) in India, 1990-2019](126).
Table 2.3 Comparison of Key Indices of India and the World

<table>
<thead>
<tr>
<th>Index</th>
<th>India</th>
<th>World</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>1.3 billion</td>
<td>7.7 billion</td>
</tr>
<tr>
<td>Human Development Index</td>
<td>0.64</td>
<td>0.73</td>
</tr>
<tr>
<td>Gender Development Index</td>
<td>0.82</td>
<td>0.94</td>
</tr>
<tr>
<td>Multidimensional Poverty Index</td>
<td>0.12</td>
<td>0.10 (Developing Countries)</td>
</tr>
<tr>
<td>Gross domestic product (GDP) per capita, USD</td>
<td>1927.7</td>
<td>10,918.7</td>
</tr>
<tr>
<td>Health expenditure per capita (USD), 2019</td>
<td>63.7</td>
<td>1,121</td>
</tr>
<tr>
<td>Out-of-pocket expenditure (% of health expenditure), 2019</td>
<td>54.7</td>
<td>18.01</td>
</tr>
<tr>
<td>Infant Mortality (per 100,000 live births)</td>
<td>27</td>
<td>27</td>
</tr>
<tr>
<td>Life expectancy (at birth), 2019</td>
<td>69.6</td>
<td>73</td>
</tr>
<tr>
<td>Total Fertility Rate (2019)</td>
<td>2.2</td>
<td>2.4</td>
</tr>
</tbody>
</table>

2020 estimates, USD = US dollars

Sources: The World Bank (171,172), United Nations Development Program (173)

India’s healthcare system includes the allopathic system along other traditional systems of medicine such as Ayurveda, Unani, and Siddha, as well as Homeopathy, collectively categorized as AYUSH (174). In urban areas, 80% of healthcare is provided by the private sector—which includes large corporate as well as smaller clinics and household-owned enterprises (141). The government spending on healthcare in India is only 1.15% of the GDP despite numerous policy statements on increasing it to 2.5%, which is required to have a minimally efficient public healthcare system (175). Along with low public spending, inadequate human resources and poor infrastructure continue to remain challenges within the public healthcare system in India. For example, more than 90% of ambulances in public tertiary hospitals have no equipment or oxygen supply and just 3% have any paramedics; as a result, they mainly function to transport dead bodies (176). Trauma patients account for 16% of total patients in these hospitals, yet they have only 3–5% emergency beds available (176). Consequently, many Indians are forced to use the largely unregulated private sector, which leads to huge out-of-pocket costs. It has been estimated that up to 40% of households in India incur catastrophic health expenditures, pushing them into debt and poverty (177,178).

The existing socioeconomic inequality of caste, religion, class, and gender in India also limits access of many marginalized groups and genders into the healthcare system leaving them unable to fulfill their health needs (179,180). Some of these challenges have been recognized by the government. There are have been policy plans to increase public spending, train more healthcare workers, create more safety nets, improve disease surveillance, and move towards universal healthcare in India (181,182). In 2018, the Ayushman Bharat scheme was started. It consolidated previous public health insurance schemes, to cover 1,400 procedures and the
cost of hospitalization for up to 15 days for low-income households (182). There are plans to cover around 500 million beneficiaries through Ayushman Bharat and set up 150,000 health and wellness centers to focus on non-communicable diseases and injuries at the primary healthcare level by 2023 (182).

There have also been some public programs and policy goals that aims to specifically meet the burden of trauma morbidity. The National Program for Prevention and Management of Burn Injuries was set up in 2010 to reduce the incidence and morbidity of burns, and the Department of Empowerment of Persons with Disabilities was set up in 2012 to meet the needs of persons with disabilities (182,183). There are plans for establishing a National Institute of Chronic Diseases and Trauma for better data collection and developing strategies for integration of a continuum of care by establishing dedicated trauma management centers—one for every 3 million of the population (182,183). While Ayushman Bharat has been able to reduce the risk of catastrophic health expenditures, funding and resources allocation seems to be affecting other initiatives (148). The implementation and efficacy of the planned actions will be assessed in the coming years.

It appears that the most of the existing research on trauma in urban India focuses on its prevention. The effect of compliance to traffic rules, the role of legislation to address mechanisms of injury like self-harm and inter-personal violence, and the need to improve pre-hospital and acute hospital care have been studied in this context. The health policies also largely focus on such preventive measures such as reducing the number of traffic injuries or falls, setting up trauma centers, improving ambulance services, provisioning of emergency care, and expanding public health insurance schemes for treatment. These are very important components of reducing the burden of trauma, but they have to be also combined with addressing what happens after the trauma.

Facilitating trauma recovery would be the next step, which would require more policies and public health programs to meet the long-term post-discharge consequences of trauma in India. The importance of studying post-discharge trauma outcomes has already been recognized in global public health and needs much more attention in India (184). Research on the nature of the recovery process for trauma patients and the different factors affecting this process in the urban Indian setting can bring this attention. Thus, addressing trauma morbidity and its long-term outcomes are an enormous public health challenges in India which requires more research and action.

2.9 Thesis framework

The existing literature indicates that there is a spectrum of different post-discharge socioeconomic and QOL outcomes that trauma patients encounter. Different research frameworks and models underscore that the pathway of recovery, for each post-discharge socioeconomic and QOL outcome, depends on environmental factors (healthcare systems, policies, physical environment, etc.), socioeconomic factors (culture, resources, etc.), and health-seeking behavior. The outcomes are also influenced by different patient characteristics
such as trauma severity. However, given that there is limited research on this in LMICs like India, this thesis will try to contribute to the evidence on these outcomes and factors associated with them among adult trauma patients in urban India. Figure 2.7, is a brief summary of the thesis study within process of recovery for trauma patients.

Fig 2.7: Thesis framework
3 THESIS RATIONALE

Trauma is an important global public health challenge with a spectrum of long-term consequences—including socioeconomic and QOL outcomes—that affect patients well beyond discharge. With more persons surviving trauma, the attention has shifted to the needs of those who survive. While it is important to continue focus on trauma prevention and improving trauma care, addressing post-discharge outcomes is crucial to reduce the trauma burden. The healthcare system can play a major role in mitigating some of these consequences along with an enhanced social welfare system.

Most of the research on how patients experience these consequences comes from HICs. While there is emerging research from LMICs, like India, it is inadequate and limited. Consequently, these post-discharge outcomes remain poorly understood in these settings. Therefore, it is necessary to understand the post-discharge socioeconomic and QOL outcomes in trauma patients in LMICs which bear a disproportionately higher burden of trauma morbidity. Studying these outcomes and the factors that affect them can help identify the needs of post-discharge trauma patients and explore how the healthcare system can contribute to their recovery.

This thesis is set in India, a country which accounts for more than one-fifth of the global trauma burden. The findings of this work may add some evidence on post-discharge socioeconomic and QOL outcomes among trauma patients and the role of different factors, such as patient characteristics, in shaping these outcomes. Additionally, it may also add to the existing body of work on predicting patient outcomes when conducting trauma research. This can contribute to the global evidence on trauma and provide some insights into how to develop policies and practices to study, improve, and strengthen existing healthcare and public services to meet the recovery needs of patients in LMICs.
4 RESEARCH AIMS

The overall aim of this thesis is to study post-discharge outcomes and factors associated with such outcomes in adult trauma patients in urban India. The specific aims were:

- To systematically assess the current evidence on post-discharge socioeconomic and QOL outcomes in trauma patients [Paper I]

- To explore the lived experience of post-discharge socioeconomic and QOL outcomes among trauma patients in urban India [Paper II]

- To develop and validate a local trauma severity model to predict trauma outcomes in adult trauma patients in urban India [Paper III]

- To investigate the interaction of factors associated with post-discharge QOL outcomes in adult trauma patients in urban India [Paper IV]
5 METHODS

5.1 Scope of thesis

This thesis assesses the existing evidence on post-discharge socioeconomic and QOL outcomes, explores the experiences of these outcomes among patients in urban India, and investigates how these outcomes are affected by patient characteristics in this setting. To achieve these aims, we started by conducting a scoping review to map the existing knowledge, in both peer-reviewed and gray literature, on socioeconomic and QOL outcomes among post-discharge trauma patients and the different tools used to measure them (80). More than 950 outcomes were identified in the review with a wide range of definitions and measurement tools. Given this variability, we selected the four most studied outcomes: QOL, RTW, social support, and social participation and selected the most widely used tools to measure them in Paper I. The scoping review also helped identify the literature sources to develop the interview tool in Paper II.

In Paper I, we assessed these outcomes in peer-reviewed research published in the last ten years. Paper II explored how post-discharge socioeconomic and QOL outcomes are experienced by trauma patients residing in urban India. It explored which of these outcomes are most common in this setting and how patients live through them as they recover from the trauma. Paper IV examined how sociodemographic factors affect the post-discharge outcomes, identified in Paper I and most common to urban Indian patients in Paper II, at different points of time after the injury. But due to the interruption and cessation of data collection due to the Covid-19 pandemic, we had to restrict Paper IV to two factors: age and sex—which emerged in Paper II as influencing post-discharge outcomes—and its interaction with a single outcome measured at a single point of time i.e., QOL at 90-days after the injury.

In order to study the interaction of different patients-related factors on the selected post-discharge outcomes in Paper IV, it was important to account for trauma severity which is an important patient characteristic that would affect any post-discharge outcome. Therefore, Paper III was conducted to develop and validate local trauma severity models that would better fit with the context of urban India. The local models were compared to one of the most widely used global trauma severity scores—Trauma Injury Severity Score (TRISS). The results of Paper III informed the methodology in Paper IV. An overview of the four papers is given in Figure 5.
Figure 5.1 Overview of the Four Paper

5.2 Overview of papers

Table 5.1 Overview of the papers

<table>
<thead>
<tr>
<th></th>
<th>Paper I</th>
<th>Paper II</th>
<th>Paper III</th>
<th>Paper IV</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Study design</strong></td>
<td>Systematic Review</td>
<td>Qualitative interview study</td>
<td>Observational multi-center cohort</td>
<td>Observational multi-center cohort</td>
</tr>
<tr>
<td><strong>Objective</strong></td>
<td>Measuring current evidence on socioeconomic and quality-of-life outcomes</td>
<td>Explore the lived experience of socioeconomic and quality-of-life outcomes in urban India</td>
<td>Development and validation of local trauma severity model for urban India</td>
<td>Interaction of age and sex on quality-of-life outcomes in urban India</td>
</tr>
<tr>
<td><strong>Data sources</strong></td>
<td>MEDLINE, EMBASE, and the Cochrane Library</td>
<td>21 semi-structured interviews</td>
<td>TTRIS (August 2016 to December 2019)</td>
<td>TAFT (November 2017 to June 2020)</td>
</tr>
<tr>
<td><strong>Analysis</strong></td>
<td>Meta-analysis</td>
<td>Thematic Analysis</td>
<td>Model building using ensemble machine learning and calibration and discrimination analyses</td>
<td>Multivariable linear regression and Multivariable logistic regression</td>
</tr>
</tbody>
</table>
5.3 Study setting

The participants for papers II, III, and IV came from six hospitals in urban India. Five of these are part of two ongoing trauma research projects that I am part of. Three hospitals are part the Trauma Triage Study in India (TTRIS) and four hospitals part of the Trauma Audit Filters Trial (TAFT) study. The aim of TTRIS is to validate and compare physician-determined triage with prediction models for use in early trauma care while TAFT assesses if institutional implementation of audit filters reduces mortality in adult trauma patients. Both TTRIS and TAFT recruit adult (18 years and above) trauma patients from the emergency department with a history of trauma—as per the V01-Y36, chapter XX of the International Classification of Disease version 10 (ICD-10) (185).

These projects have dedicated officers who prospectively enroll patients and collect data on patient demographics, injury etiology, vital parameters, and treatment interventions using standardized procedures. The project officers work in alternating eight-hour shifts of morning, evening, and night followed by day off. They also follow-up patients to collect project-specific outcomes such as mortality and QOL at fixed time points. The data collected by the project officers is deidentified and uploaded to a central database and subject to regular reviews and quality control assessments by the members of the project. The sixth hospital was not part of these projects, and was selected later to arrive at the required sample size for a representative sample Paper II as consenting participants from a single site who fit the eligibility criteria were not adequate.

These six hospitals are located in four major cities in India: Delhi, Mumbai, Bengaluru, and Kolkata. These cities are large urban agglomerations with a combined population of more than 57 million residents (Mumbai: 18.4 million, Delhi: 16.3 million, Kolkata: 14.1 million, and Bengaluru: 8.4 million) (186). Five of the hospitals are tertiary teaching hospitals; four of which are public while one is a non-profit charitable private hospital. The remaining hospital is a secondary public hospital. The public hospitals provide free treatment to the patients charging a nominal user-fees. Majority of patients who use these public hospitals are from low-income and socially marginalized groups. The non-profit private hospital caters to patients who fully pay for their treatments as well as patients who pay highly subsidized fees. This hospital has patients from both high- and middle-income as well as low-income groups.

Tertiary public hospitals tend to be main sites for referral and management of trauma in urban India due to injuries being classified as medico-legal in India, limited infrastructure and resources in primary or secondary public hospitals, and the exorbitant cost of care or refusal to treat in private facilities (187). Trauma patients would either be transferred from secondary and primary public health facilities or private health facilities of all levels from within the cities and surrounding rural and semi-urban areas.

As mentioned above, most of the patients in the six hospitals come from low socioeconomic groups. They tend to live in slums or low-cost apartments within the city or peripheral areas that are poorly constructed living quarters without adequate water and drainage facilities, and
usually with outdoor communal latrines. Many of these dwellings are illegal with narrow unpaved roads and susceptible to environmental and man-made hazards. Many of the patients are migrants from other parts of the country and are employed as daily wage or in manual jobs. Consequently, the residents from these settings are in general characterized by poor health outcomes (188). There are also some middle-income patients who have better living and employment conditions.

5.3.1 Study Sites

Maulana Azad Medical College & Lok Nayak Hospital, Delhi (LNP)

Lok Nayak Hospital (LN) is a tertiary public hospital established in 1936 as the Irwin hospital in central Delhi and renamed in 1977. It is attached to the Maulana Azad Medical College. LNP has 1000 beds Lok Nayak Hospital with a 24-hour emergency department (ED) and a 30-bed intensive care unit (ICU). It includes departments for General Surgery, Neurosurgery, Orthopedics, Burns & Plastic Surgery, and Anesthesiology.

Institute of Post-Graduate Medical Education and Research & Seth Sukhlal Karnani Memorial Hospital, Kolkata (SSKM)

Established in 1707 and opened to Indians in 1770, Seth Sukhlal Karnani Memorial Hospital, Kolkata (SSKM) is a public tertiary hospital in Kolkata. Formerly known as the Presidency General Hospital, it is a 1775-bedded hospital and one of the few public hospitals in eastern India that has a department for Neurosurgery along with General Surgery, Orthopedics, Burns & Plastic Surgery, and Anesthesiology and is attached to the Institute of Post-Graduate Medical Education and Research. In 2019, a 300-bed trauma center was set up with 24 ICU beds and a dedicated ED. Burns patients are still received and treated in the main hospital building.

St. John’s Medical College, Bengaluru (STJ)

St. John’s Medical College, located in Bengaluru, was established in 1963 and is attached to a 1350 bed hospital with around 90 critical-care beds across different specialties. It is a private charitable tertiary-care referral hospital. It has a common ED where all patients regardless of cause are received.

Grant Government Medical College & Sir Jamshedjee Jeejeebhoy Hospital, Mumbai (JJ)

Established in 1845, in south Mumbai, the Sir Jamshedjee Jeejeebhoy Hospital is a public tertiary hospital with 2844 beds. It has a 24-hour ED that receives all patients and has emergency ward with 20 beds. Along with General Surgery is has super specialty departments such as cardiothoracic surgery, Neurosurgery, Plastic surgery, and Pediatric surgery.
Figure 5.2 Location of study sites within India and Mumbai

Map Source (189,190)

Legend

🌟 Maulana Azad Medical College & Lok Nayak Hospital, Delhi
🌟 Institute of Post-Graduate Medical Education and Research & Seth Sukhlal Karnani Memorial Hospital, Kolkata
🌟 St. John's Medical College, Bengaluru
🌟 Grant Government Medical College & Sir Jamshedjee Jeejeebhoy Hospital, Mumbai
🌟 KB Bhabha Hospital, Mumbai
🌟 Lokmanya Tilak Municipal General Hospital & Medical College, Mumbai
KB Bhabha Hospital, Mumbai (KBBH)

KB Bhabha Hospital is a public secondary hospital with 436 beds built in 1914. Located in western Mumbai, it has a 24-hour ED with a 15-bedded ICU. It has an Orthopedics and General Surgery Department and treats minor to moderate traumas while advanced interventions are referred to other public tertiary hospitals in Mumbai.

Lokmanya Tilak Municipal General Hospital & Medical College, Mumbai (LTMGH)

Lokmanya Tilak Municipal General Hospital & Medical College is a 1416-bed public tertiary hospital in central Mumbai. It has a 14 bed ICU dedicated for trauma patients as well as departments of General Surgery, Neurosurgery, Orthopedics, Plastic Surgery, Pediatric Surgery, and Anesthesiology.

LN, SSKM, and KBBH are the sites for the TTRIS project while LN, SSKM, STJ, and JJ are sites for the TAFT project. The location of the 6 study sites within India is given in Figure 5.2.

5.4 Study design and methods

5.4.1 Paper I

Paper I was a systematic review to assess the current knowledge on four commonly used socioeconomic and QOL outcomes in post-discharge trauma patients measured by two of the most widely used tools for each outcome informed by the scoping review (Table 5.2). The review included studies reporting these outcomes among adult (18 years and above) trauma patients up to a year post-discharge. We excluded studies that only included specific body parts injured such as traumatic brain injuries or spinal cord injuries. This was done as we wanted to focus on trauma as a whole rather than cohorts of specific body parts injured studied in isolation. Most trauma patients do not arrive with just one type of trauma. Trauma management does not target specific injured body parts, rather trauma as a whole is treated at the healthcare facility.

Table 5.2 List of Outcomes and Measurement Tools Used in Paper I

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Measurement Tools</th>
</tr>
</thead>
<tbody>
<tr>
<td>Return-to-work</td>
<td>Back to any work (Yes/No)</td>
</tr>
<tr>
<td></td>
<td>Sick leaves or Days off</td>
</tr>
<tr>
<td>Social Support</td>
<td>Support from family, friends, and neighbors (Yes/No)</td>
</tr>
<tr>
<td></td>
<td>Multidimensional Scale of Perceived Social Support (MSPSS) (87)</td>
</tr>
<tr>
<td>Social</td>
<td>Craig Handicap Assessment and Reporting Technique (CHART) (91)</td>
</tr>
<tr>
<td>Participation</td>
<td>Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) (92)</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>Rand’s Short-Form (SF-36/12) (82)</td>
</tr>
<tr>
<td></td>
<td>Euro Quality of Life (EuroQol: EQ-5D) (83)</td>
</tr>
</tbody>
</table>

Source: Paper I
The search was conducted on MEDLINE, EMBASE, and the Cochrane Library for the last 10 years from the date of the search. For this paper we used the Preferred Reporting Items for Systemic Reviews and Meta-Analyses (PRISMA) guidelines to report the results (191) and the review was registered in the PROSPERO International Register of Systematic Reviews (192). The studies were screened by two independent reviewers and data was extracted about the characteristics of the study population, injury severity, study design, location and setting of the study, and the outcome estimates. We also appraised the methodological quality of the studies by using the Joanna Briggs Institute (JBI) Critical Appraisal Tools Checklist (193).

We performed data-pooling and meta-analysis, where ever possible, after sub-grouping based on the outcome, measurement tool, type of effect measure, study setting (high-, middle-, or low-income country), age, and gender. $I^2$—a measure of statistical heterogeneity—was computed using the restricted maximum-likelihood estimator. We performed data-pooling and derived forest plots using the statistical software R (194). In cases where meta-analysis was not possible, we used narrative synthesis. We also performed sensitivity analysis by doing a leave-one-out analysis for studies that had scored higher than the mean methodological appraisal score across the studies.

5.4.2 Paper II

In Paper II, we conducted semi-structured interviews to explore the lived experiences of socioeconomic and QOL outcomes in post-discharge trauma patients. We chose this approach as we wanted to collect descriptive information on the participant’s account of these outcomes with the scope to probe on specific emerging areas during the interviews. We recruited participants between April 2019 and December 2020 from JJ and LTMGH in Mumbai using purposive sampling to make a representative sample of different mechanisms of injuries (falls, road traffic injuries, burns, and railway injuries) and demographic groups. We excluded intentional injuries like self-harm and assaults, keeping in mind the psychosocial health of the patients in mind. We included patients living within the city of Mumbai and between three and twelve months of discharge so that they could describe the range of outcomes they experienced.

We discussed and derived the interview guide based on evidence reviewed in the scoping review [Appendix 1]. The interview guide was piloted for appropriateness and revised based on responses of the participants. I selected discharged patients from the medical records at the two hospitals and contacted them by telephone to describe the study and request their participation. If they agreed to be part of the study, I conducted a face-to-face interview at a time and place most convenient to them. They were assured anonymity and confidentiality, and written and verbal consent was taken for the interviews. The interviews were audio recorded and field notes were maintained. The interviews were conducted in local languages (Hindi, Marathi, and English), after which I transcribed them directly into English. After removing any personal identifiers, the transcripts were securely stored in a digital format.
Halfway through the data collection, the Covid-19 pandemic and related restrictions disrupted the face-to-face interviews for nearly a year. Keeping in mind the safety of the patients and my own and the time constraints of the doctoral study, after deliberations with my supervisors, it was decided to conduct the interviews via telephone. Verbal consent was taken from the participants with permission to record the call. After reviewing the interviews, we came to a consensus on when data saturation had been reached and then stopped contacting more patients.

We used thematic analysis in this study to generate codes and categories from the transcripts of the interviews. I followed Braun and Clarke’s approach to identify the initial codes and categories inductively and deductively for a few transcripts (195). This was reviewed and discussed with my supervisors and based on their inputs this process was completed for all the transcripts. Sub-themes and themes were created reflecting similarities and associations between the codes and categories. This was again discussed and reviewed by the rest of the team. To enhance the trustworthiness of the study, I documented all the decisions made during the study along with maintaining a reflexive process journal. Additionally, we periodically discussed the transcripts, interview experiences, and my own reflections.

5.4.3 Paper III

In Paper III, we wanted to develop a local trauma severity model using an ensemble machine learning algorithm and to compare it with a widely used global trauma severity prediction model TRISS. TRISS has been seen to have poor performance in LMIC settings like India. We hypothesized that developing a local model to adjust for severity in the urban Indian context might be better suited for analyzing the interaction of different patient factors on post-discharge outcomes in Paper IV. In this study we used data from the TTRIS project from LN, SSKM, and KBBH hospitals. In this study we included data of 12,324 trauma patients arriving at these sites between August 2016 to December 2019.

We developed two local models for this paper. For local model-1 we selected variables from literature and consulting with clinicians working in trauma care management in urban India. It included patient vitals: systolic blood pressure (SBP), respiratory rate (RR), heart rate (HR), oxygen saturation (SPO), and Glasgow Coma Scale (GCS); injury etiology: mode of transport, type of injury, mechanism of injury, and injury severity scores (ISS); and demographic measures: age and sex. For local model-2 we used only demographic and physiological scores: age, sex, SBP, HR, RR, SPO and GCS. The TRISS model is derived using the Revised Trauma Score (RTS) based on GCS, SBP and RR along with age and type of injury (blunt or penetrating). Additionally, we also developed an updated TRISS model using coefficient cut-offs derived from the study population. The main outcome was 30-day mortality.

To develop the local models, we split the dataset into two. A training sample—80 % of the dataset—to generate the three local models and a test sample—20% of the dataset—to assess and compare the performance of the models with TRISS. We used the ensemble machine learning procedure SuperLearner to derive the local models (196).
combines different statistical techniques to create a prediction model that best fits the selected variables and outcome in a given dataset, then performs cross-validations, and creates a model using an optimal weighted average of the different statistical techniques used (an ensemble). Following recommendations for prediction models and assuming a 30-day mortality rate of around 8% from previous research, we estimated that a sample size of at least 667 would be required for the study (197,198). We used multiple imputation, based on the percentage of missing across each variable, to handle missing data (199). We used a predictive mean matching to impute continuous variables like age or GCS, logistic regression imputation for binary variables like 30-mortality, and polytomous regression imputation for categorical variables like mechanism of injury.

We assessed the performance of the models using discrimination—the ability to assign higher scores to those with a higher probability of mortality and calibration—how well the model’s predicted mortality coincided with the actual observed mortality (200). We measured discrimination and calibration using area under the receiver operating curve (AUROC) and integrated calibration index (ICI), respectively (201). These were reported with corresponding 95% confidence interval (95% CI). We also estimated the models’ performance using bootstrapping (202). We used R for all statistical analyses (194) and reported the study findings using the Transparent Reporting of a multivariable prediction model for Individual Prognosis Or Diagnosis (TRIPOD) guidelines (203).

5.4.4 Paper IV

**Paper IV** was a cross-sectional study to assess the interaction of age and sex with post-discharge QOL at three-months after the injury. We selected age and sex as it emerged as key factors shaping post-discharge outcomes in the urban Indian setting in **Paper II**. We used deidentified data of 631 trauma patients admitted at LN, SSKM, JJ, and STJ between November 2017 and June 2020 from the TAFT dataset. The main variables were sex (female and male) and age (categorized as young adults-18-32 years, middle-aged adults-33-59 years, and old adults-60 years and above). We used the physiological variable-based model from **Paper III** as it performed the best among all the models to adjust for trauma severity in this study. QOL measured using the EQ-5D Tool was the main outcome for this study EQ-5D measures quality of life using five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression with responses as: no problems, some problems, and extreme problems as well as a visual analog scale (VAS) for rating the health status (204).

We used multivariable logistic regression to study the association of age and sex with the different domains of EQ-5D and multivariable linear regression for the health status. We studied the interaction between age and sex using the product of age and sex. We corrected the effects of multicollinearity, we estimated results at 95% confidence intervals, denoted associations with a p-value of less than 0.05 as statistically significant, and used R for all the analyses (194,205). Based on previous studies, we determined that at least 160 subjects are required for each of the three responses across the five EQ5D domains (206–208). In order to have adequate sample sizes we combined the three responses into two "Having no problems"
and "Having any problems". Similarly, for the analysis with health status a minimum sample of 16 subjects was estimated to be required (207).

5.5 Ethical considerations

**Paper I** was a systematic review and meta-analysis of peer-reviewed papers published in scientific journals. Ethical approval was not sought as it did not directly involve the research participants. The difficulties of ascertaining if adequate ethical considerations were met in the studies included for systematic reviews is a challenge recognized in research (209). In **Paper I**, we assumed that all the papers included in the study would have been assessed for the required ethical approvals during the peer-review process at each journal. However, it is possible that some ethical issues may have been overlooked or not considered.

For **Paper II**, ethical approval was sought from one study-site to identify patients from the hospital medical records and telephonically contact them to seek permission to participate in the study. In the second site, an amendment was obtained from the institutional ethics committee to identify potential participants from the on-going TAFT project to contact and seek permission to be part of the study. The interviews were scheduled at a time and place most convenient to those who agreed to participate. All the participants preferred to be interviewed at home and a time was selected to limit interfering with their daily routine.

The choice of place and time for the interview sometimes led to interruptions by family members, household chores, or surrounding commotion. Care was taken to reduce these disruptions by scheduling or rescheduling interviews to times with least interruptions and selecting a spot away from potential distractions. However, these disruptions were not fully unavoidable in smaller homes situated in densely inhabited areas. The presence of family members or impending chores can affect the responses of the participants. On the other hand, conducting the interviews at the home of the participants, helped in placing the post-discharge outcomes and challenges described by the participants in the context of their living environment. As a researcher, who comes from a different socioeconomic setting this was especially insightful in my understanding of the lived experience of post-discharge outcomes.

The first wave of the Covid-19 pandemic and the subsequent lockdowns struck in the middle of the interviews. Consequently, the interviews had to be stopped for months. Additionally, the participants contacted beyond this period often expressed discomfort to have the interviews conducted at home. Especially, by someone who is coming through a hospital—which were then perceived to be hotspots for Covid-19 infection. Keeping in mind the time and resource constraints of completing the study as part of my doctoral thesis, it was agreed with the supervisors to conduct the interviews via telephone. This curtailed the advantages of face-to-face interviews and the opportunity of observe the participants environment.

Before each interview the participants were explained the purpose of the study, assurance of confidentiality and anonymity, and that they were free to not answer any question they chose not to or discontinue the interview at any point. Written consent was then obtained from the participants and a patient information sheet describing the study as well as contact my details.
For those patients who opted not to sign the written consent form, verbal consent was taken and recorded. For the interviews conducted over the phone only verbal consent was possible. We came to an agreement that no financial renumeration would be given for participation in the study. This was to remove the influence of such compensation on participation. The interviews were scheduled to reduce any loss of income or intrusions to the lives of the participants.

It was anticipated that while revisiting the trauma or talking about post-discharge socioeconomic and QOL outcomes, topics that were sensitive and emotional would come up. Since I had no psychological training, it was decided that the best option was to give the participants the option to stop the interview and either reschedule or withdraw from the study assuring them that no part of their interview would be used for the study. Additionally, a contact list of psychological support helplines and professionals were carried by me at all times to share with the participants. Moreover, it was also decided to exclude those trauma patients who had intentional injuries (self-harm and assault) as the stated mechanism of injury in the medical records as I was not equipped to handle the unique psychosocial needs of such patients during the interviews.

**Paper III** and **Paper IV** used deidentified data from the on-going TTRIS and TAFT projects, respectively. The data collected is uploaded to a combined online database after all patient and hospital identifiers have been removed. Most of the variables collected in these projects are routine patient data collected at the study sites as part of treatment and the projects did not affect the clinical management of these patients. The institutional ethics committees at the five hospitals in these projects granted waiver for informed consent for demographic parameters and vital signs. Informed consent was sought from the patients for follow-up via telephone to collect patient outcomes such as QOL. Since, all the data was collected by dedicated project officers, it is possible that their presence in the ED may have diverted the attention of the treating physicians. However, the project officers have been trained to be inconspicuous not interfering with any treatment procedures.

We tried to uphold the principles of medical ethics as part of this thesis to the best of our abilities (210). To ensure patient autonomy, the consent process in **Paper II**, was kept voluntary. In **Paper II** and as part of the TTRIS and TAFT projects in **Paper III** and **IV**, participants were given detailed information about the study or the projects. Patient Information Sheets were provided to all the participants with details about the purpose of the research and contact details of the site investigators for any questions they may have [Appendix 2, 3 & 4]. It was also clarified they were under no obligation to consent to participate and refusal will not hinder any treatment or care from the hospital. Participants were assured verbally about the confidentiality of their data which was deidentified before making it available for any research. I tried to reiterate these points to participants during the interviews so that they do not feel pressured or compelled to respond or participate.

In term of beneficence, we felt that that though the participants may not directly benefit from participating in the research, the findings of the studies may help other trauma patients or
themselves if they were injured again. We also believe that most of the data used in Paper III and IV would not potentially harm the patients most of it is part of routine data collected in the hospitals as part of trauma management. However, data collected in Paper II and the QOL outcomes used in Paper IV has the potential of eliciting emotional feelings or stress. I and the project officers collecting this data tried to be as empathetic and sensitive as possible while asking these questions and suggesting possible ways to seek help for any potential emotional issues that may come up. This included referring them to relevant physiotherapy, psychiatry, or outpatient departments in public hospitals or sharing helplines that they could seek support.

List of ethical approvals

Paper II

b. Institutional Ethics Committee Human Research, Lokamanya Tilak Municipal Medical College & General Hospital, Mumbai, India: IEC/52/19 dated 09.01.2020 (IEC/49/20, dated 28.01.2020)

Paper III

a. Institutional Ethics Committee, Maulana Azad Medical College and Associated Hospital, New Delhi, India: F.1/IEC/MAMC/(53/2/2016/No.97) dated: 15.09.2016
c. IPGME&R Research Oversight Committee (Institutional Ethics Committee), Institute of Post-Graduate Medical Education and Seth Sukhlal Karnani Memorial Hospital (IPGMER & SSKM), Kolkata, India: Inst/IEC/2016/328 dated: 22.06.2016
d. Regionala etikprövningsnämnden i Stockholm, Dnr 2018/2201-31/2

Paper IV

a. Institutional Ethics Committee, Maulana Azad Medical College and Associated Hospital, New Delhi, India: F.1/IEC/MAMC/(57/02/2017/No.113) dated: 19.07.2017; F.1/IEC/MAMC/(72/07/2019/No.29) dated: 03.03.2020
b. IPGME&R Research Oversight Committee (Institutional Ethics Committee), Institute of Post-Graduate Medical Education and Seth Sukhlal Karnani Memorial Hospital (IPGMER & SSKM), Kolkata, India: Inst/IEC/2016/328 dated: 22.06.2016
c. Institutional Ethics Committee, Grant Government Medical College & Sir JJ Group of Hospitals, Mumbai, India: IEC/Pharm/CT/111/A/2017, dated 22.08.2017
e. Regionala etikprövningsnämnden i Stockholm, Dnr 2017/930-31/2.
5.6 Reflections from the field

Though I have been associated with the Towards Improved Trauma Outcomes-India (TITCO) consortium, which runs the TTRIS and TAFT projects, for a few years before my doctoral study, I had not directly worked with trauma and its long-term physiological, functional, psychological, and socioeconomic outcomes. I had spent some time being mentored by one of my supervisors—Harris, a medical anthropologist with extensive experience working with trauma patients in India. It helped me grasp some basic understanding of conducting field work with trauma patients. As a project manager in the TITCO-India consortium, I had usually seen trauma patients as data points, sample sizes and cohorts for analysis. Through this doctoral journey, especially through Paper II, I understood that there was a face, a voice, and a life story behind each data point. It was of individuals and their families adjusting to this single unexpected event—a trauma.

It was in this process of adjusting to the severe functional, complex social, and costly economic consequences of their trauma that I was meeting them. As a researcher, I had my own biases coupled together with my social and economic privilege, different from the participants. Moreover, without experiencing trauma myself or being treated in same facilities as them or living in the same environment as them, made it difficult for me to understand the experiences of the participants. Yet, almost all the participants welcomed me into their homes and shared their narratives. Most were very forthcoming about their views on their post-discharge lives, while others, quite naturally, felt I might not understand their perspective.

I also learnt to be mindful of the power dynamics of being a researcher. Given the difference in the socioeconomic backgrounds and that I came through the hospital, the participants might have felt obliged to participate. I kept reminding the participants during the interviews that they did not have to answer everything or choose to stop the interview without it affecting them seeking care at the study hospitals. It also meant being observant of trivial things such as how I dress, sit, and accepting water or some other refreshments after politely refusing at first. It was also an opportunity to be careful of my own biases and interpretations of their responses. I tried to obtain their narratives rather than focusing on just getting the responses to my questions. I also stuck to their own phrases and language during the translation process to keep the narratives as close as possible to the original without losing their intended meaning.

Another area that was difficult for me to navigate was not trying to confront some of the prejudices or stereotypes a few of the participants brought up. These were to do with religion, caste, and gender. For example, some participants who were involved in road traffic crashes with someone from a different community, did blame the crash on group stereotypes. I did try to suggest possible alternate explanations, beyond these stereotypes, for some of these comments. I also tried to steer the conversation away from that point. But it was a challenge to avoid confronting these beliefs that I do not agree with. Related to this, was evading giving my own personal views or suggestions about certain dilemmas participants would raise and restricting my interaction to being a good listener.
Another challenge that I faced in the field was being able to interview females, especially younger females around my own age. Trauma predominately affects younger- and middle-aged males in India. This meant that the proportion of potential female trauma patients to interview was already small to begin with. Given the sociocultural norms in the study context, it was difficult to secure interviews from younger females. Some females refused to be interviewed at all. At times during the interview, it was awkward to talk about certain issues such as self-care or hygiene. So, it was understandable why females, especially younger females, may have chosen to not participate. We involved a female interviewer to accompany me whenever possible. It did help in female participants opening up more. Additionally, as discussed before, females report trauma due to gender-based violence as other non-intentional injuries at the hospital (211). Such survivors would not want to be part of interviews which could threaten their privacy and safety.

Given the complex psychological and social facets of intentional injuries like self-harm or assaults and my lack of psychosocial training for the same, it was decided to not include intentional injuries as part of the field-work. Self-harm was only decriminalized in India in 2018 and there is prevailing social stigma around it therefore, such cases are often not disclosed or wrongly reported in the health system (212). During the field work, I did come across two such cases, which were revealed mid-way through the interview. In a third case, the participant was withdrawn during the interview and gave answers to describe how the injuries—which were lacerations on both her wrists—happened.

At such moments it is difficult to choose the right course of action. Does one stop and not engage further for fearing of doing unintentional harm or should one hear out the person who has opened up about their pain. It was a dilemma deciding the right course of action in each of these cases keeping in mind to do no harm to the participant. I stopped the first two interviews and asked if they wanted to continue. One participant continued with the interview and asked me it was up to me include his story in my research. I did not include his interview in this analysis. The other participant did not want the interview to be used but wanted me to go on with the questions. He said that it felt nice to talk to someone about it. I spoke to him and never continued the interview. For the third participant, I wrapped up the interview. I gave all of them a list of psychological helplines or clinics that they could use which I carry during every interview.

In the first two situations I felt that I should listen to the participants without judgement or giving any suggestions while being kind and empathetic. For, the third participant it felt best not to engage. But it was very hard to decide how to deal with such situations on the field despite prior preparations or planning. Discussing these dilemmas with my supervisor—Harris—helped me distill my own perspectives and build my skills in handling such situations guided by ethical principles and participant welfare. It was also a realization that one cannot create a single fool-proof perfect research plan but that ethical considerations would have to be revisited and reviewed throughout the research process.
Listening to the range of challenges and consequences faced by the patients was often quite moving and emotionally draining. It was difficult to not be personally affected and not try to go beyond my role as a researcher to help them. I had kept the contacts of some community-based-organizations (CBOs) and non-profit-organizations that they could approach to assist with some of their needs. But not all the problems that came up could be addressed that way. Unfortunately, there were not a lot of people I around I could share this with after each interview. The isolation from my peers and support systems during the pandemic made it worse. Periodically discussing and debriefing with my two of supervisors Harris and Martin did help. Nevertheless, this was an opportunity for me a researcher to also learn to self-soothe and detach from the research participants while being sensitive, considerate, and empathetic to their experiences.

There were biases that were embedded in the research process. My own biases as a researcher because of my personal beliefs, research experiences and the literature review would have made me seek certain types of information confirming what I read or feel about the experiences of trauma patients. This would have led to me overlooking information that came through the data collection or data analysis process. On the other it is possible that the respondents, during the interviews or while providing data as part of the TTRIS and TAFT projects, may decide to share or answer depending on what they feel I want to hear or taking cues from what questions I am asking. Moreover, they may also choose to discuss or give socially acceptable answers. I tried to reduce some of my confirmatory bias by recording the interviews and taking detailed notes during the interviews so that everything was being captured and not just what I felt was important. Review of the transcripts by my supervisors also helped in identifying some of my biases. I also tried to build trust with the respondents and making them feel comfortable by spending time asking general questions and reiterating the purpose of the interviews. However, it was not possible to eliminate these biases completely.

Through this doctoral process a point of contention that I encountered was the variance of opinion on what is considered “relevant”, “significant”, or “valid”, or research. Some of my clinician, statistician, and natural scientist colleagues would be vary about certain qualitative methods and findings being clinically relevant, statistically significant, or scientifically valid. Discussing with my multidisciplinary peers at KI did help in such situations. It also made me aware of my own views of the superiority of certain methods over others. I have come to see that different research methods, especially in health, approach the same problem in different ways and seek to answer it differently. Some address the why and how and others how much and to what extent. Some are exploratory and others are confirmatory. This determines what assumptions are made, how data is collected and analyzed, and how results are interpreted. As long as the principles of each research method are being followed all types research findings can be relevant, significant, and valid.

Being the project manager of TITCO-India consortium involved running the day-to-day program of the TTRIS and TAFT projects, supervising the project officers at the different
study sites, and coordinating with the finance and administration officer. Though, I had the handful of members of the TITCO-India consortium to consult with, I had to figure many things out by myself as I went. It was an opportunity to learn, err, and understand my strengths and limitations on managing human resources and balancing finances. The project officers were collecting data at the hospitals in different cities, each site with its own challenges. I had no experience working in the tough hierarchical bureaucratic hospital space to discernibly understand these challenges. Even with the commitment from both sides, it was challenging to oversee the work while pushing officers to be involved in the research process. I am not sure how successful I was, but some of the project officers have been able to go beyond data collection and become budding researchers.

Another aspect that often popped up in my reflections, was that while my thesis findings may at some point help future trauma patients, the participants themselves would not be directly benefiting from my study. One of the aims of every doctoral research is to contribute to adding evidence on a topic but is this a substantial benefit. It is possible the knowledge that this thesis adds may not improve the post-discharge outcomes for trauma patients. I sometimes wonder if creating evidence, is the best utilization of the resources being used in my doctoral research? But then I feel that maybe this is the pragmatic outcome of such research—the hope that at some point in the future the little evidence that is added through my doctoral research maybe used to expand the evidence base and eventually push for some change in policy or practice. Maybe highlighting some of the problems faced by my research participants can lead to more for research and subsequently in the future lead to improving services for trauma patients.
6 RESULTS

6.1 Patients remain affected up to a year post the trauma [Papers I, IV]

Of the 11,774 articles screened, 43 were included in the systematic review in Paper I. The meta-analysis showed that at six months only 52% of trauma patients had returned to work. Even after one year more than one-third (37%) of the participants had yet to return to any form of employment. Among trauma patients who did return to work (RTW), it took, on average, three and half months to recover and get back to work. Studies included in the review also reported moderate social support received by trauma patients.

The results from Paper I also showed that, even though there were improvements over time, quality of life (QOL) among post-discharge trauma patients had not improved to the pre-injury level or the baseline population level even after one year. Similar findings were observed in Paper IV where the mean EQ-5D VAS score of 76.6 (SD = 20.5), reported among 631 adult trauma patients in urban India three months after the trauma, was lower than the general population norm for India of 80.

Additionally, in Paper IV only half of the trauma patients reported being able to move around with no problems at three months post-discharge. Less than half reported being able carry on their usual activities without any problems, and two-thirds of all trauma patients reported having pain at three months post-discharge. Around two in five trauma patients reported experiencing some form of anxiety or depression (Table 6.1).
Table 6.1 EQ-5D score and percentages reported in Paper IV

<table>
<thead>
<tr>
<th>EQ-5D Domain</th>
<th>Levels</th>
<th>Score/Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Status (mean [SD])</td>
<td></td>
<td>76.6 [20.5]</td>
</tr>
<tr>
<td>Mobility (%)</td>
<td>No Problems</td>
<td>347 (55.0)</td>
</tr>
<tr>
<td></td>
<td>Some Problems</td>
<td>207 (32.8)</td>
</tr>
<tr>
<td></td>
<td>Confined to bed</td>
<td>77 (12.2)</td>
</tr>
<tr>
<td>Self-Care (Number %)</td>
<td>No Problems</td>
<td>402 (63.7)</td>
</tr>
<tr>
<td></td>
<td>Some Problems</td>
<td>175 (27.7)</td>
</tr>
<tr>
<td></td>
<td>Unable to wash or dress</td>
<td>54 (8.6)</td>
</tr>
<tr>
<td>Usual Activities (Number %)</td>
<td>No Problems</td>
<td>268 (42.5)</td>
</tr>
<tr>
<td></td>
<td>Some Problems</td>
<td>240 (38.0)</td>
</tr>
<tr>
<td></td>
<td>Unable to perform usual activities</td>
<td>123 (19.5)</td>
</tr>
<tr>
<td>Pain/Discomfort (Number %)</td>
<td>No Pain</td>
<td>215 (34.1)</td>
</tr>
<tr>
<td></td>
<td>Moderate Pain</td>
<td>388 (61.5)</td>
</tr>
<tr>
<td></td>
<td>Extreme Pain</td>
<td>28 (4.4)</td>
</tr>
<tr>
<td>Anxiety/Depression (Number %)</td>
<td>No Anxious/depressed</td>
<td>371 (58.8)</td>
</tr>
<tr>
<td></td>
<td>Moderately Anxious/depressed</td>
<td>192 (30.4)</td>
</tr>
<tr>
<td></td>
<td>Extremely Anxious/depressed</td>
<td>68 (10.8)</td>
</tr>
</tbody>
</table>

6.2 Trauma patients in urban India experience recovery as incomplete, expensive, and inter-social [Papers II, IV]

In Paper II, we performed thematic analysis on interviews of 21 participants discharged from two tertiary public hospitals (JJ and LTMGH) in Mumbai, India. It had been three to eight months since their trauma. Our analysis identified three main themes in their post-discharge experience (Figure 6.1).

Recovery is incomplete

The interviewed participants reported that had not yet completely recovered from their trauma. Most of them continued to faces challenges in getting back to their pre-trauma life. This included pain, being unable to move around without assistance, and performing selfcare tasks such as bathing or using the toilet. The environment they lived in—the squatting toilets, staircases, transportation options—exacerbated these problems. Participants also spoke about facing psychological and emotional stress about the trauma and its consequences in their lives. However, they did not seem to consider or seek medical care for their pain or psychological conditions. They also pointed out the barriers of accessibility, availability, and affordability for good-quality follow-up treatment. Similar findings were seen in the analysis from Paper IV where pain, inability to perform usual activities, and psychological morbidity were the pain drivers for poor QOL. Nearly 60% of study population had problems with their usual activities,
two-thirds reported some form of pain, and around 40% of the participants reported some form of anxiety and depression.

*Figure 6.1 Summary of Themes from Paper II*

---

**Recovery is expensive**

Participants recounted the different expenses they incurred post-discharge. These included direct costs such as medicines, follow-up treatment, and cost of transportation for the treatment. Participants also spent money on making structural changes to their living environments—for example, constructing indoor toilets or purchasing adult diapers—to facilitate post-discharge mobility and self-care, and on legal fees for certain mechanisms of injury like road traffic crashes. Loss of income due to participants and their caregivers being absent from work or losing jobs was another financial burden reported. Not being able to return to work was reiterated by almost all working participants as one of their biggest post-discharge concerns. All these costs ate into their savings, forced them to sell family assets including gold and property, changed their consumption patterns, and pushed them to borrow money. This pushed most of them into debt.

**Recovery is intersocial**

The participants’ accounts showed how their social characteristics played into their post-discharge outcomes. Social grouping (caste and religion), income level, and living situation (type of family: married, single, children, parent) seemed to influence their recovery. The nature and extent of social support they received was determined by these characteristics, and consequently affected their socioeconomic and QOL outcomes. Neighbors, friends, social group members, spouses, children, and parents were the main support systems participants reported. They contributed in physical, economic, and specifically caregiving roles. These were additionally influenced by age and sex. The role of age and sex was also observed in the results of the sub-group analysis in *Paper IV*. Females reported lower health status than males across all age groups, except middle-aged adults. However, middle-aged females reported having
problems across most of the domains of QOL. It was older adults who had the lowest scores for health status among all groups. Higher odds of reporting psychological morbidity were reported among specific demographic groups, namely, young-females and middle- and old-aged males.

6.3 Locally developed models are better suited for adjusting for trauma severity in academic research [Paper III]

The results of Paper III report the discrimination—if the higher scores correspond to higher mortality—of the four models: Local model-1, Local model-2, the original TRISS model, and the updated TRISS model. Discrimination was calculated as the area under the receiver operating curve (AUROC), and were 0.96 (95% CI 0.82 - 1), 0.96 (95% CI 0.81 - 0.99), 0.96 (95% CI 0.81 - 1) and 0.91 (95% CI 0.8 - 0.97), respectively. The receiver-operator characteristics curves for the models are shown in Figure 6.2. Thus, the local models had slightly better discrimination.

The calibration—if the predicted mortality coincides well with the observed mortality—was calculated as mean Integrated Calibration Index (ICI) values for the models, were 0.04 (95% CI 0.01 - 0.04), 0.14 (95% CI 0.07 - 0.17), 0.03 (95% CI 0.01 - 0.05), and 0.04 (95% CI 0.03 - 0.11), respectively (Table 6.2). Therefore, the two local models had the best calibration. The calibration curves are shown in Figure 6.3.
Table 6.2 Calibration Metrics associated with 95% confidence intervals of the four models in Paper IV

<table>
<thead>
<tr>
<th>Calibration</th>
<th>Local Model-1</th>
<th>Local Model-2</th>
<th>Original TRISS Model</th>
<th>Updated TRISS Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICI</td>
<td>0.04</td>
<td>0.03</td>
<td>0.04</td>
<td>0.14</td>
</tr>
<tr>
<td></td>
<td>(0.01 - 0.04)</td>
<td>(0.01 - 0.05)</td>
<td>(0.03 - 0.11)</td>
<td>(0.07 - 0.17)</td>
</tr>
<tr>
<td>E50</td>
<td>0.01</td>
<td>0.01</td>
<td>0</td>
<td>0.01</td>
</tr>
<tr>
<td></td>
<td>(0 - 0.02)</td>
<td>(0 - 0.02)</td>
<td>(0 - 0.03)</td>
<td>(0.01 - 0.02)</td>
</tr>
<tr>
<td>E90</td>
<td>0.08</td>
<td>0.05</td>
<td>0.14</td>
<td>0.37</td>
</tr>
<tr>
<td></td>
<td>(0.02 - 0.1)</td>
<td>(0.03 - 0.1)</td>
<td>(0.05 - 0.27)</td>
<td>(0.03 - 0.21)</td>
</tr>
<tr>
<td>Emax</td>
<td>0.51</td>
<td>0.31</td>
<td>0.74</td>
<td>2.43</td>
</tr>
<tr>
<td></td>
<td>(0.18 - 0.7)</td>
<td>(0.23 - 0.85)</td>
<td>(0.52 - 3.03)</td>
<td>(0.21 - 1.86)</td>
</tr>
</tbody>
</table>

This shows that, overall, Local Model-2 had better discrimination and calibration for predicting 30-day mortality while Local Model-1 underestimated the probability of mortality. The TRISS models could separate those who die from those survive (good discrimination) but overestimated the risk of mortality in this population. Therefore, Local Model-2 can be used in
academic research in studies on trauma patients in urban India and other similar study populations to adjust for trauma severity.

6.4 Post-discharge socioeconomic and quality of life outcomes are shaped by age and sex among trauma patients in urban India [Papers I, II, III]

Findings from sub-group analysis in Paper I indicate that older trauma patients had lower QOL index scores compared with other adults (EQ-5D Index score of 0.46 vs 0.62). Participants in Paper II described how older adults with trauma would find it difficult to receive support and have poorer post-discharge socioeconomic and QOL outcomes than others. In Paper IV, after adjusting for trauma severity, the EQ-5D health status reported by the study population indicated that older adults had the lowest health status (Table 6.3).

Table 6.3 Adjusted EQ-5D health status across age and sex categories in Paper IV

<table>
<thead>
<tr>
<th>Sex and Age Categories (n)</th>
<th>EQ-5D Score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
</tr>
<tr>
<td>Male 18-32 years (244)</td>
<td>80.5</td>
</tr>
<tr>
<td>Male 33-59 years (197)</td>
<td>74.4</td>
</tr>
<tr>
<td>Male 60 years and above (47)</td>
<td>75.2</td>
</tr>
<tr>
<td>Female 18-32 years (52)</td>
<td>79.9</td>
</tr>
<tr>
<td>Female 33-59 years (65)</td>
<td>77.8</td>
</tr>
<tr>
<td>Female 60 years and above (26)</td>
<td>74.1</td>
</tr>
</tbody>
</table>

Study I showed that most studies reported that men had better RTW, QOL and social support outcomes than women. Participant narratives in Study II suggest that women participants had to include doing household chores and childcare, in addition to formal employment, as part of returning to work. The self-care needs of women participants were also more challenging to meet as it was felt that only other women could help them. Due to social norms, women were expected to be the primary caregivers for their male relatives and not the other way round. Additionally, caregiving of women trauma patients was restricted to doing the household chores or childcare tasks for them.

Paper IV highlights that at three months post-trauma, females reported lower QOL scores than men (Table 6.3). The only exception was the middle-aged cohort. Old-aged females reported the lowest QOL across all groups. Middle- and older-aged females also had more odds of having pain, problems with performing usual activities, and barriers to self-care than males of the same age (Table 6.4). On the other hand, younger-aged females and middle- and older-aged males reported higher odds of having anxiety and depression than their opposite sex counterparts. This psychological morbidity appeared to be the main driver of low QOL scores in these groups. This suggests the possible intersectional nature of the interaction of age and gender in post-discharge socioeconomic and QOL outcomes in urban India.
Table 6.4 Adjusted odds ratio of reporting any problem in the EQ-5D domains across different groups in Paper IV

<table>
<thead>
<tr>
<th>Group</th>
<th>Mobility</th>
<th>Self-Care</th>
<th>Usual Activity</th>
<th>Pain/Discomfort</th>
<th>Anxiety/Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OR</td>
<td>95% CI</td>
<td>OR</td>
<td>95% CI</td>
<td>OR</td>
</tr>
<tr>
<td>Male 18-32 years</td>
<td>Reference group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male 33-59 years</td>
<td>0.77*</td>
<td>0.51</td>
<td>1.15</td>
<td>0.72</td>
<td>0.39</td>
</tr>
<tr>
<td>Male 60 years and above</td>
<td>0.66</td>
<td>0.5</td>
<td>1.0</td>
<td>0.69</td>
<td>0.46</td>
</tr>
<tr>
<td>Female 18-32 years</td>
<td>0.79</td>
<td>0.4</td>
<td>1.4</td>
<td>0.52</td>
<td>0.28</td>
</tr>
<tr>
<td>Female 33-59 years</td>
<td>1.48</td>
<td>0.61</td>
<td>3.39</td>
<td>1.11*</td>
<td>0.48</td>
</tr>
<tr>
<td>Female 60 years and above</td>
<td>0.75</td>
<td>0.23</td>
<td>2.57</td>
<td>0.95</td>
<td>0.30</td>
</tr>
</tbody>
</table>

Adjusted for age, gender, and trauma severity; OR, odds ratio; CI, Confidence Interval; * statistically significant at 0.05
7 DISCUSSION

The main findings of the thesis indicate that the effect of trauma on post-discharge socioeconomic and quality of life outcomes is long-term, the recovery process is incomplete, expensive, and inter-social in urban India, locally developed models can predict trauma mortality with good discrimination and calibration, and that age and sex interact to affect post-discharge socioeconomic and quality of life outcomes in the urban Indian context.

7.1 The effect of trauma on post-discharge socioeconomic and quality of life outcomes

The results from Paper I show that the effect of trauma on post-discharge outcomes—specifically return to work (RTW) and QOL—extends beyond a year after discharge. Similar findings have been reported in other reviews on specific types of trauma and large population registries (213–217). Apart from trauma severity, RTW is determined by the nature of pre-trauma employment—those in professional jobs had higher rates of RTW than those engaged in blue-collar and manual jobs (218). Higher socioeconomic status and education are also shown to positively affect RTW (219,220). Age and sex are also associated with RTW in trauma patients (221). Similarly, studies have pointed out that along with trauma severity, age, sex, RTW, social support, psychological morbidity, economic burden, and socioeconomic status affect QOL in trauma patients (222–224). Social support has been shown to improve RTW, mental health, and QOL, which is relevant given that Paper I indicates trauma patients receive only moderate support (224–227). Thus, like the ICF model points out there are different factors affecting the consequences of trauma which need to be considered in order improve recovery and address the burden of trauma (69).

Paper I reiterates that most research on post-discharge socioeconomic and QOL outcomes in trauma patients comes from high-income settings. This skewed representation in research has also been observed in different sub-groups within trauma (228–230). Examining the remaining studies, indicates that these predominately come from middle-income countries with little to no evidence from low-income countries. This was also seen in the scoping review that we conducted (80). A recent review of the burden of trauma in LMICs highlighted the need for broader representation of evidence from different LMICs in order to fill the knowledge gap of research from LMICs (231). Paper I also reports that studies from LMICs were of lower methodological quality. The paucity of funding for high-quality research in LMICs as well as the exorbitant costs of publishing papers in scientific journals are held responsible for this (232,233). However, it appears that both these issues seem to be inadequately addressed. This needs to be kept in mind for future research.

7.2 The socioeconomic and quality of life outcomes of post-discharge trauma patients in urban India

The post-discharge trauma participants in Paper II experienced pain, lack of mobility, and burden of self-care to be the main factors affecting them even after six months post-discharge. This was also reported in Paper IV, with lack of mobility, the inability to carry on usual activities, and pain still affecting around half of the post-discharge trauma patients at
three months. Pain in particular was still reported by two-thirds of participants. Trauma patients have reported pain as one of the most prevalent QOL domains, across settings and types of traumas, during various points in their recovery up to a year (234–238). The interviews in Paper II reveal that pain relief was not provided to the participants. There is documentation that unavailability, costs, legal complexities, and clinician perceptions are barriers in prescribing pain relief medication in India (239–241). Therefore, treatment and management of pain should be included as part of follow-up care for trauma in India.

Paper IV also reports that nearly 40% of participants reported having some form of anxiety and depression. This is higher than recent studies on trauma patients from India and Sweden using the EQ-5D tool (234,242). Paper II also highlighted the psychological problems faced by post-discharge trauma patients. Analysis of the National Mental Health Survey (2015-2016) showed that while the prevalence of depressive disorders in adults in India was around 4%, in persons with disabilities it was as high as 78% (243). As psychological morbidity continues long after trauma, it is important to consider screening and treating for specific temporary and life-long prevalence of mental health disorders in trauma patients (244–246). However, it is not adequately recognized or diagnosed due to the precedence of other pressing medical conditions due to the trauma (247). Mental health continues to have low prioritization in India and subsequently this affects assessment and treatment of psychological conditions, with nearly two-thirds of those diagnosed with mental health conditions in urban India not being treated (243,248).

Paper II also reported that post-discharge trauma patients could not access well-resourced, affordable, and good-quality healthcare after discharge. Some also felt that they had not fully recovered at discharge and that spending more time in the hospital would have reduced their post-discharge follow-up needs. Participants also had to bear considerable economic hardships due to the trauma they had suffered. Trauma and its consequences have been shown to lead to catastrophic health expenditures in countries with limited social security safety nets like India (183,249–251). Improvements in emergency care services have reduced in-hospital trauma mortality and more trauma patients survive in India (252). Given the need for follow-up services and treatments among post-discharge trauma patients—especially for those with physical impairments—it is important to provide affordable and accessible continuum care for improving the recovery process in LMICs (253–256). The WHO’s “Rehabilitation 2030 Initiative”, focuses on addressing this gap, and pushes for integration of rehabilitation services as part of universal health coverage (112). This is in line with the Trauma Outcomes Model (71) that stressed the need for integrating affordable follow-up services within the healthcare system and improving its reach. Both are important in the urban Indian setting.

Another aspect of the urban Indian experience of post-discharge socioeconomic and QOL outcomes, that emerged in Study II, is the role of support from family, friends, and community members. In order to cope with the plethora of challenges faced by participants, this social support seemed indispensable. The role of social support in improving different
post-discharge outcomes among trauma patients has been observed in other studies on trauma across the world (257–260). More exploration into how the nature and extent of social support affect post-discharge outcomes, in this setting, will give insights into the interaction of social support and patient outcomes. A key form of social support, reported in Study II, was caregiving. These were informal roles, provided usually by female relatives, undertaken along with the regular professional or domestic tasks of caregivers. Informal caregiving is necessitated by the lack of affordable formal caregivers or caregiving institutions. Literature from other settings highlights the heavy toll on the physical and mental health of caregivers (261–263). However, the challenges faced by informal caregivers in the Indian setting is poorly understood. This can, in turn, identify specific needs of informal caregivers and formulate context-specific solutions to address them.

7.3 Developing local scoring and prediction models for trauma research

Paper III shows that, on the whole, the local model based on physiological variables (local model-2) has superior discrimination and calibration in predicting 30-day mortality than the, global gold standard: TRISS. The discrimination of the four models (the two local models, the original TRISS model, and the updated TRISS model using the study population) was comparable. The original TRISS model had slightly lower discrimination. Similarly, the calibration scores of the two local models were similar to the original TRISS model. The updated TRISS model had the lowest calibration. Nevertheless, the calibration was not extremely inferior compared with the other three models. Many studies have reported that TRISS has comparable discrimination to other prediction models and poor calibration in different settings and populations (264–269), including India (270,271).

The slight underestimation of mortality by local model-2 in the calibration slopes could be due to the absence of any anatomical trauma variables in the model. It has been suggested that some anatomical component is required to accurately measure trauma severity (272). Conversely, the study population was largely composed of mild injuries, and thus low ISS. This would affect the ability of any model that uses ISS—the local model-1 and both the TRISS models—to differentiate between mild and severe injuries. Moreover, having a low mortality rate in this population indicates that the mortality could be largely clustered around the few severe injuries. This is possibly why the calibration curves of these three models overestimate mortality at moderate and higher scores and underestimates mortality at lower scores. Using standardized data collection processes, having low proportion of missing variables, and not missing injuries—as the study population was mostly mild trauma—could have reduced the proclivity of misclassification. This is one of the reasons that TRISS is said to perform poorly in some settings (273,274). The overall calibration score in Paper III was not extremely poor though the calibration curve was overestimating mortality.

Given the mixed results on TRISS’s ability to predict mortality in different settings, especially LMICs, there have been recommendations to modify it to be better adapted to different settings. Some suggest replacing a few of its component variables like ISS with the New Injury Severity Score (NISS) and respiratory to more updated, easily measurable, and
routinely collected physiological variables like oxygen saturation, while others recommend revising the cut-offs (275–277). More research on such recalibrated coefficients and new variables are important for assessing the application of TRISS in different settings, especially LMICs. Since **Paper III** indicates that local models can better predict mortality than TRISS in the urban Indian trauma population, these models can be used in academic research and in quality improvement programs to adjust for trauma severity or derive prediction models. However, more research on the use of such models in different trauma populations within India and other LMICs is required.

### 7.4 The role of age and sex on post-discharge socioeconomic and quality of life outcomes among trauma patients in urban India

**Paper IV** reported that though females have slightly better overall QOL, when sub-grouped by age, only middle-aged females performed better than males. In the general population in India, males have higher QOL scores than females (278). Existing evidence on trauma patients from other settings, as well as that from **Paper I**, reports males outperforming females on post-discharge QOL (52,67). The difference in the middle-aged cohort in **Paper IV** is not very clear. A recent study on trauma patients from India, also showed that females had better QOL scores than males (242). This needs more research from other settings in India to substantiate the role of sex on QOL post-trauma. Additionally, persons who do not belong to heteronormative sex groupings tend to have poorer post-discharge outcomes after trauma due to the discrimination and marginalization they face (279). Outcomes of this vulnerable cohort has not been covered in this thesis.

QOL decreased over age, with old-aged females having the lowest health status across all groups. This could be attributed to comorbidities, frailty, and limited social capital among older adults (55,280,281). Furthermore, older females are especially vulnerable because of their poor access to resources and support in India (144,282). This makes geriatric trauma at risk for poor post-discharge outcomes in the Indian context. In **Paper IV**, middle-aged females had the highest odds for reporting problems across most QOL domains—mobility, self-care, usual activities, and pain—yet they do not perceive their overall health status to be very low. The reasons for this are not very clear. Based on Anderson’s behavioral model it is possible that this is related to the low healthcare-seeking behavior among females in India (120). Sociocultural factors can compel females to overlook their health problems and downplay them; consequently, they do not consider these as affecting their health or warranting intervention (283).

Young females and middle- and older-aged males had the highest odds of depression and anxiety in **Paper IV**. In general, females show a higher prevalence of depression and anxiety in the Indian population (284). The role of sex and depression in trauma patients has been quite mixed; rather, factors such as life satisfaction, employment, and self-efficacy have been shown to be more strongly associated with depression (285–288). Trauma in younger females could be more likely due to gender-based violence, which affects their psychological well-being. They are also more likely to be engaged in formal employment and domestic
chores than older females and prospects of marriage and employment among young disabled females can be quite diminished in India (289,290). These could be possible reasons they report more depression and anxiety.

Not able to return to work or support their families among males in our study setting—in the Indian context males are responsible for earning income—may contribute to a feeling of helplessness, which could explain the higher odds of psychological morbidities among them. Additionally, impaired or reduced sexual functioning has been shown to be a major source of depression and psychological stress in males after trauma (291,292). This could have exacerbated depression among males in this context. On the other hand, middle- and older-aged females may not disclose conditions that may be socially stigmatizing (293). There is also evidence that spirituality can be a protective coping mechanism from depression in trauma patients (294–296). As middle- and older-aged females tend to be more engaged in such observances in India, it could contribute to the lower odds of depression reported in them. These findings suggest intersectionality of age and sex might be influencing QOL outcomes in post-discharge trauma patients in urban India. More longitudinal and qualitative studies on different domains of QOL among different age and sex sub-groups can lead to a deeper understanding on these interactions.

Trauma in urban India should also be placed in the larger context of structural factors such as inequality. Risk to certain mechanisms of injury such as transport injuries, falls, occupational injuries, and violence are embodied in the everyday socioeconomic inequalities present in urban spaces in LMICs. For example, poor transport infrastructure, poor quality of vehicles, and compromising of safety by overworked road users increases the risk for transport injuries (297,298). On the other hand, inequality also limits opportunities for recovery after trauma. It determines the availability and affordability of quality care, options and resources to travel for such care, and limited employment opportunities to work with trauma-induced disabilities. These vulnerabilities cannot be remedied by just enforcing and promoting regulations and behaviors. It would require addressing the underlying causes of this structural inequality within urban the environment. Any policy for reducing trauma burden should be mindful of this.

7.5 Summary of findings from the thesis

The findings of this thesis identified more factors that affecting post-discharge socioeconomic and QOL outcomes among trauma patients in urban India besides trauma severity. Our findings indicate that age and sex play a crucial role in determining these outcomes. They interact and affect how these outcomes are experienced by different demographic groups given the sociocultural context of the papers. The nature of healthcare services: availability, affordability, and social support was also observed as factors affecting these post-discharge outcomes. We postulate that there would be other factors such as socioeconomic status which can influence the outcomes and determine how these outcomes evolve during recovery process. Future research can build evidence on different post-discharge outcomes and identify
factors relevant in the context of urban India and other LMICs. A graphical representation of this is given in Figure 7.1.

Fig 7.1 Summary of thesis findings

7.6 Methodological considerations

The four studies in this thesis have different biases and limitations that affect the applicability of the findings.

7.6.1 Paper I

In the systematic review we used MEDLINE, EMBASE, and the Cochrane Library. These three databases include a variety of different journals with peer-reviewed articles. However, these are not exhaustive sources and it is likely that some of the articles would have been missed, leading to a selection bias. Similarly, only using English language studies would have the same effect. We included studies using two of the most widely used tools to measure post-discharge outcomes. This would omit studies reporting the outcomes using other measures. Thus, the findings are not a comprehensive overview of trauma outcomes. As mentioned earlier, most of the studies included in the review came from high-income settings. The results would be a reflection of this setting, limiting the transferability of the findings of the review to other LMIC settings, which have a disproportionately higher burden of trauma.
The appraisal of the studies is subjective. Though two reviewers independently appraised the quality of the studies and mutually came to a consensus, it is possible that their biases would have affected the process.

The included studies had a lot of heterogeneity. Some used only a specified range of trauma severity, some excluded certain groups like amputees and older adults, while others only included patients with certain mechanisms of injury. We included studies reporting outcomes up to one year, but all studies did not have the same end points. We could not factor in all of these differences when pooling data. We tried to reduce this by using random effects meta-analyses to allow for heterogeneity and performing sensitivity analysis. Additionally, as smaller studies have greater representation in random effects meta-analyses, it would have made the results prone to publication bias and amplify variability between studies. In this review, we wanted to study the prevalence of post-discharge outcomes in the trauma population as a whole. Therefore, we excluded studies that involved isolated body part injuries. Analyzing trauma of different body parts separately would have led to sharper results. However, trauma is neither presented nor managed in the healthcare setting as specific body parts and any change in policy or practice will not target trauma in just one body part.

7.6.2 Paper II

We tried our best to make the participants representative of trauma patients, by including different age groups, sexes, mechanisms of injury, and body parts injured. We were not able to include certain groups such as spinal cord injuries and transgender persons. We had also specifically excluded patients who had intentional injuries such as assault and self-harm. Therefore, the findings are not representative of the experiences of all trauma patients. All participants were residing in a single city, Mumbai. While it is the largest city in India, it does not fully represent urban India. This limits the generalizability of the study to urban India as a whole. We interviewed patients at a single point of time after their discharge; thus it would reflect their experiences up to that point. Nevertheless, the findings do give an overview of how post-discharge socioeconomic and QOL outcomes are experienced in urban India.

Using the findings from our scoping review and Paper I to develop the interview tool helped in structuring the questions around different standardized socioeconomic and QOL outcomes. It also helped in the thematic analysis process to generate codes and categories deductively. On the other hand, this meant that we had to use and translate certain terms and concepts from English into Hindi and Marathi. This was difficult for certain terms, for example, “mobility”, “self-care”, and “quality of life”. We had to derive questions that unpack these terms to elicit appropriate and relevant responses from participants. We did test them with our colleagues in the field, but it is possible that the meanings may not have been fully captured. Conversely, while analyzing the transcripts, certain texts could be interpreted differently, attributed to different domains, and coded differently. We tried to minimize this subjectivity, by discussing the initial codes and categories that were assigned to the transcripts within the research group. Additionally, there were difficulties in clearly separating the codes and
categories for some domains of the outcomes, as they were closely connected and interdependent.

Trustworthiness is an important aspect of interpreting data in qualitative research. It involves credibility, or whether the study represents the experience of the participants; dependability, or whether the study process is detailed; confirmability, or whether the study has interpreted the data correctly; reflexivity, or whether the researcher affects the study; and transferability, or the generalizability of the findings to other contexts (299). This can be done in various ways by triangulating the data collected, maintaining field notes and reflections, debriefing with team, and reviewing and arriving at consensus on themes with the research team. The home visits were an opportunity to gather data by observing participants’ environments, perusing documents such as medical reports, receipts or medications, as well as having informal conversations with participants and their caregivers. This helped in triangulating the data collected during interviews. It was also an opportunity to build trust with the participants through direct interactions that would help them open up during interviews. Unfortunately, this could not be done with telephonic interviews. An audit trail was maintained with all decisions taken during each stage of the study from planning to data collection to analysis as well as field notes. Periodic meetings with the team were held to review the work.

In order to account for reflexivity, it was important to recognize the characteristics of the research team. I have been engaged in public health research for more than a decade. Being from Mumbai and part of the on-going trauma projects (TTRIS and TAFT) in public hospitals in different cities in India, I am more familiar with the context. It also helped me in conducting interviews and analyzing the data. The team involved researchers who have closely worked in the context of trauma in Mumbai in particular, India as a whole, and in global health in general. Our positions and perspectives would have informed the entire study, but it was also an opportunity to learn about the context and explore different ways of interpreting the data. To minimize the influence of the team, periodic reviews and discussions between authors of the paper were held, and we strove to adhere strictly to principles of thematic analysis.

7.6.3 Papers III and IV

The data used for these papers came from the TTRIS and TAFT projects. The data was collected by dedicated project officers who prospectively collected data using similar well-calibrated devices. The collected data was de-identified and reviewed weekly by a core group of trauma clinicians. The project officers were deputed at different sites to review the data collection process of other project officers. Project officers were periodically given re-fresher courses on the data collection procedures. However, human errors in collecting the data are possible. The data was coded for the Abbreviated Injury Scale (AIS)—an anatomically-based injury severity scoring system—to calculate the Injury Severity Score (ISS) to be used in the models. There could be potential biases in the coding process even though we tried to address this by having experienced and trained coders. Additionally, the study sites are mainly high-volume, overburdened, low-resource tertiary public hospitals, and advanced imaging
diagnostics such as CT-scan machines may not be always be available for every patient. This could possibly lead to missing certain injuries, affecting the calculation of ISS.

In **Paper III**, we used 30-day mortality as the outcome and it is possible that every death at 30 days may not be directly related to the trauma. But then, using any cut-off time for mortality would have some drawbacks. In **Paper IV**, the QOL outcomes were collected at a single point of time and could not observe changes in QOL across time between different age and sex groups. The QOL outcomes were collected telephonically. Even though all the instruction given by the EQ-5D manuals were followed, it is possible that questions could be misinterpreted or misunderstood and affect the responses. Additionally, there were female and male project officers collecting the data. It is possible that the sex of the project officer asking about outcomes influenced the reporting of QOL by the participants. The missing data in both studies are not randomly distributed between different survivors and across the EQ-5D domains and scores, resulting in a bias. While it is possible that patients who died or had very poor QOL outcomes may have been lost to follow-up, we cannot determine or estimate the direction or the extent of this bias. Both the projects exclude trauma patients who were dead on arrival at the study site, leading to an optimistic biasing of mortality as it is very likely that patients who die on their way to the hospital had more severe trauma.

In **Paper III**, the study population comprised mainly of patients with mild severity and blunt trauma. In **Paper IV**, the study population had a mix of different severities, but again consisted predominately of blunt trauma. It also only captures those who responded during the follow-up calls, leaving out drop-outs. Moreover, the patients in both papers tend to represent mostly low- and some middle-income urban populations. Thus, it is likely that both study populations are not fully representative of the trauma population in their respective cities, or urban India. This affects generalizability to other settings, which may have a different case-mix of trauma patients. However, they do provide some insights into developing local models and the interaction of age and sex on QOL in urban India and other LMICs. Both the papers would have to be replicated in different settings to validate their findings.
8 CONCLUSIONS

1. Patients report poor socioeconomic and quality of life outcomes beyond a year after the trauma. Even after one year, a third of trauma patients have not returned to work and their quality of life has not reached pre-injury levels [I, IV].

2. Trauma patients in urban India experience post-discharge recovery as incomplete, expensive, and inter-social. Social support was an important mechanism to bear these consequences [II, IV].

3. Locally developed models are better suited for prediction of outcomes and can be used in academic research on trauma patients [III].

4. Post-discharge socioeconomic and quality of life outcomes are affected by the age and sex among trauma patients in urban India. Older females have the lowest health status while middle-aged females have the highest odds of having problems across different QOL domains. Inability to perform usual activities, persistence of pain, and presence of psychological morbidity affect more than half the trauma patients at three months [I, II, IV].
9 IMPLICATIONS FOR FUTURE RESEARCH AND PRACTICE

9.1 Research

Findings from Paper I underscores the need for more high-quality research from LMICs to study the post-discharge socioeconomic and QOL outcomes among trauma patients. Longitudinal cohort studies that follow-up patients at specific intervals would build robust evidence on the extent and patterns of these outcomes in these settings. Given, the variability of outcomes and tools, using standardized terms and well validated and widely used tools will add value to the studies and enable comparison with other settings.

Qualitative research can shed light on how post-discharge socioeconomic and QOL outcomes are experienced by different mechanisms of injury in different geographic settings by different sociodemographic groups, especially vulnerable groups like the aged, females, and trans persons in India. Given the high burden of self-harm, the trajectory of recovery in this group would be particularly relevant in urban India.

Paper IV demonstrates that factors age and sex do interact and influence post-discharge outcomes in this setting. This interaction needs to be further probed through cohort studies and qualitative research. The interaction of other relevant variables like caste, religion, and socioeconomic status needs to be included in future research.

Given that social support is a such an important factor in modifying the experience of post-discharge socioeconomic and QOL outcomes, further exploration on how support can affect outcomes should be undertaken. These studies could look at how different types of support: spousal, familial, and societal or communal support can differentially affect outcomes.

As informal caregiving was crucial to post-discharge recovery, more in-depth studies looking role of caregivers is required. Exploring the challenges they face, coping mechanisms they use, and the support they require, especially in LMIC settings, is warranted.

More research on the performance of different trauma outcome prediction models, both local and global, in different cohorts of trauma patients and in different settings can help build the evidence on their efficacy and accuracy. This will help in improving existing models and developing appropriate context-specific models of prediction in trauma research.

9.2 Practice

Addressing the global burden of trauma is not just about preventing deaths and saving lives, but also facilitating the recovery of patients after discharge. This requires more research to understand the extent and nature of the challenges faced by patients during their recovery. This could be met by funding more studies on post-discharge socioeconomic and quality-of-life outcomes, building the capacity of health facilities to collect patient outcome data for research, and including patient-reported outcomes as part of clinical research.
Healthcare providers should screen and investigate for pain and psychological conditions among post-discharge trauma patients during their follow-up visits to detect, diagnose and treat accordingly. There are simple screening tools that can be used at the point of discharge or in out-patient settings which can be incorporated as part of follow-up care by healthcare providers.

Integration of different post-discharge follow-up services, especially physiotherapy, pain management, and psychological services, within the public healthcare systems can provide affordable, accessible, and good quality care to trauma patients. This would require allocating more resources for such integrated trauma care and pushing for inclusion of rehabilitation as part of essential and universal care. In the context of India, it would be implementing the policies of “health and wellness centers” and increase public spending on health to at least 2.5% of GDP.

The role played by larger structural inequalities in trauma should be kept in mind when developing programs for the healthcare system to facilitating recovery. A potential solution could be distributing the rehabilitation services within the primary, secondary or peripheral healthcare facilities rather than at the trauma center or the overburdened tertiary care hospitals. This would enable more people to access these services by overcoming some of the barriers of cost and limited means of transportation to healthcare care facilities.

Policy-makers should explore ways on developing and strengthening safety nets and welfare programs to meet the extended consequences and catastrophic costs of healthcare among post-discharge patients. In India, this would mean allocating more resources as part of the existing public health insurance scheme, Ayushman Bharat, to increase its beneficiary base, range of services included, and empaneled hospitals.
10 ACKNOWLEDGEMENTS

First and foremost, my deepest gratitude goes to all the patients who opened their homes and hearts to me and shared their stories without expecting anything in return. Thank you for letting me use your experiences as part of this research.

I was lucky to have four amazing people as my supervisors.

**Martin**, my friend and main supervisor. Firstly, thank you for letting me be your first doctoral student. You consistently, politely, and patiently put up with me. You always gave me your undivided attention. I have not had a single “horror story” or any complaints about you as a supervisor. You ensured I was on track while letting me make my own mistakes. You jumped in or threw the life-jacket when required, never letting me sink. There was always a place for me in your schedule and at your dining table. Your commitment, focus, and passion will always be the gold standard for me both in work and in life. Thank you for everything!

**Dr. Roy**, this would have been possible without you: the opportunities you opened up for me and the people you introduced me to. I will always be grateful to you for that. Thank you for pulling me up when I needed it and trying to instill in me a sense of focus, consistency, and planning. Thank you for showing me that, apart from resources, there aren’t that many differences between people in low-, middle-, and high-income settings. I still don’t know how you manage to all that you do—clinician, teacher, mentor, policy-maker, coordinator—and still be so much to so many of us.

**Harris**, you developed in me such a deep admiration for research in general, and qualitative research in particular. The warmth with which you approach research, your dedication, and being methodological yet pragmatic in the field is an art you’ve managed to cultivate to perfection. You helped me nurture these skills through practice and I’ve learned so much watching you do it. Our time in Mumbai, conducting interviews and discussing things from food to movies to politics, was among the most memorable and rich moments of my life.

**Cecilia**, thank you for making me a priority and for always having time and feedback to give me. Every time we spoke, you had something practical and positive to say, with a gentle laugh. Even with the multiple responsibilities and students you manage, you always knew what I needed to do, both academically and administratively. You helped me place my work beyond the lens of trauma, onto the wider context of public health. Thank you for being the repository of almost all the knowledge about Stockholm and KI and for doling it out over meals with me.

**Monty**, thank you for agreeing to be a mentor and discussing with me my future and goals.

I am grateful to all the project officers of the TITCO-India consortium: **Tamal, Surbhi, Ranit, Manjula, Jyoti, Kunal, Greeshma, Deepak, Debojit, Chandrika**, and **Anna**. Your work made this research possible. I hope all of you use research to build your expertise.
Anna, thank for agreeing to be part of the research work. Your curiosity and enthusiasm are assets in being the good researcher that you are becoming. Please don’t lose it.

Santosh, you have been my pillar and partner in crime for the last eight years in trying hard, making mistakes, and making sense of managing the work projects. Thank you for going out of your way and beyond your job description to be my only “work-friend.” I would not have made it through my PhD and projects without you. You are a great family man!

To the members of the TITCO-India consortium: Kapil, Deepa, Vineet, and Nakul, thank you all for letting me be part of your surgical world. Thanks to all the Principal Investigators and Co-Investigators of the Trauma Triage Trial Study (TTRIS) and the Trauma Audit Filter (TAFT) project sites: Rajdeep Singh, Anurag Mishra, Makhan Lal Saha, Shamita Chatterjee, L N Mohan, Akshai CK, Sendhil Rajan, Girish Bakhshi, Shraddha Dhende, Chandrakant Sable, Sanjay Nagral, and Nitin Borle.

To the Thursday Truth Seekers Club, Mumbai for giving me an opportunity to share my research and providing me with feedback as well as opening the world of health research to me. I’m happy to keep seeking with you! Dr. Anita, Bhakti, Prashant, and especially Rakhi for her feedback. Dr. Tamhankar for always having a word of encouragement for me.

A special thanks to Johan, for always making me feel welcome and sharing your thoughts and insights. Especially, for introducing me to Candyland, the global cultural and artistic melting pot in the middle of Stockholm. To Martina (the kindest person I have met) for all your encouragement. Good luck with your doctoral work! To Anneli for all the affection, discussions, and for opening your home to me.

To all my colleagues at Global Public Health, Bérangère (multi-tasking with her PhD), Winfred (balancing clinical work with her PhD), Nada (superhumanly managing cooking, Zumba, completing her PhD, and brainstorming restaurant ideas), Shweta (my fellow warrior in the last battle for the PhD) Jhon, Constance, Regine, Sara, Reza (for all the valuable suggestions) and so many others. How you guys manage research, work, and fun is still beguiling to me. To amazing senior colleagues who have broadened my perspective towards research through their insights: Tobias Alfvén, Mariano Salazar, Stefan Fors, Karl Gauffin (Stockholm University), Anna Hildenbrand-Wachmeister, and Ziad Khatib. To all the administrative colleagues who work behind the scenes to make things work: Anastasia, Véronique (for always replying calmly to all my frantic emails), Emma (for arranging everything), and Bo. A very special thanks to Claudia for agreeing to be my chair. To Tim, Ann-Charlotte, and Madeleine for going through my raw drafts and sharing your feedback.

To Dell, thank you for showing me how to navigate and complete a PhD and for our support group. To the other member of the group, Johanna, the Gracious Mountain, thanks for showing me the light at the end of the tunnel, taking me around Sweden, and for always
pulling me out of my despair with just a phone call. You and Joakim are amazing people and hosts!

My deepest gratitude to Vijji, for being not just an administrative colleague, but my Mumbai-kar bahin. Along with Jagdish, you made it feel just like home. My doctoral experience would not be the same if it were not for you. Aashi, your creativity, curiosity, and intellect are gifts. Thanks for designing my thesis cover. I am anxiously waiting for that ice-cream and the wonderful things you will achieve.

To my three dearest kompisar, Ivan, Magda, and Vera. You are my favorite Swedes. You make Sweden special for me. Thank you for shinning into my life. Må ni leva i hundra år! Thank you so much Anna for letting me into your home and showing me that not all Swedes are data-oriented humanoids. But most of all for making Martin seem more human to me.

To Nya Pulsen for being my comfort zone, stress-buster, and helping me experiment with my culinary and life skills.

To my friends—Shruti for being the Omani cowgirl of all my public health adventures in Mumbai and conquering the world of development in your ballerina shoes and hairbands. To Alan, for all those drives, talks, and restaurant hopping; keeping rocking the world in Dubai.

To Robbie and Anand for all the love, food, trips, and letting me act like a brat even 1900 kilometers away. To my best friend Zubin, for being my constant source of comfort, humor, and support in person and over 12,000 kilometers and 12 time zones away. You not only edited what I wrote but also encouraged me at every step of the PhD. Your perseverence, patience, and ability to adjust is inspiring!

To my larger family thank you for all your support. Especially Dyson Pappen who inculcated in me as a child the love for reading everything and anything. And for making me feel the PhD was worth it. To my nephews and nieces for giving me a reason to do the work I do. Thanks to my cousins and in-laws for letting me be more than just Sidhu Appa/Mama/Pappen/Uncle to my nephews and nieces. And to my frenemy Joseph, I do miss you, hope to see on top of your game in Bangalore.

To my wonderful in-laws for believing in me so much and getting me a PhD gift seven months before my defence. Thank you for making me feel like your son. Irene I would have not been able to finish my work if not for your laptop.

Last but not the least, my dearest loving family: Mummy and Sherin. Thanks a million for putting up with me and letting me get away with “I cannot do that”, “I am in class”, “I am on a call”, well most of time. I would not be here without Mummy by my back and Sherin by my side. I love you unconditionally forever! Daddy, I wish you were here. I hope this makes up for me being a lousy athlete.
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12 APPENDIX 1: INTERVIEW TOOL (PAPER II)

A. Background
1. Could you tell me a bit about yourself?
   - Age, religion
   - Family
   - Education/Work

2. How long have you been staying here?

3. Could you describe what happened to you?

4. How long were you in the hospital?

5. How long since you were discharged?

6. Could you describe the problems you faced at discharge?

7. What are the medicines or treatments you are taking right now?
   - Drugs, medical treatments, hospital, doctor visits, follow-ups

8. Could tell me where you are going to seek the above treatments?
   - Hospital (private/public), clinic, family or neighborhood doctor

9. Could you tell me why do you seek treatment there?
   - Location, costs, better service, etc.

10. Could you describe the physical problems you face right now?
    - Disability, movement, pain, sleep, memory, bodily functions (eating, drinking, excretion)
    - Writing, reading, picking objects
    - Co-morbidities

B. Outcomes
1. Social
   i. Since the injury what kind of difficulty do you face in mobility? (capacity)
      - Walking, sitting, sleeping

   ii. What kind of assistance do you require for the above activities? (performance)
      - How frequently?

   iii. Since the injury what kind of difficulty do you face doing the activities at home? (capacity)
iv. What kind of assistance do you require for these activities? (performance)
   - How frequently

v. Since the injury what kind of difficulty do you face doing activities outside the house?
   (capacity)
   - Shopping
   - Travelling
   - using services like school, hospitals, religious places

vi. What kind of assistance do you require for these activities? (performance)
   - How frequently

vii. How has the injury affected the kind activities and functions are you able to attend?
     - Functions, festivals, gatherings, etc.

viii. What is the support that you require from your family, friends and community?
     - Primary care giver/s

ix. How do you feel about the support and behavior of your family, friends and community
    since the injury?

2. Economic

(Direct)

i. Could you describe the costs due to the injury?
   - Ambulance or transport, Hospital treatment, drugs, tests, follow-up (medical)
   - changes around the home (wheel chair, changing toilets, etc.), care-takers costs, legal services
     (non-medical)

(Indirect)

ii. How has the injury affected your work/job?
   - What are the difficulties faced in performing the work? Assistance required?
   - Support from work place
   - How long did/will it take for you to get back to your work?
   - Could you estimate the costs due to missing work?
- How do you feel that the injury has affected your job-opportunities?

iii. Could you tell me how you were able to meet the expenses due to the injury?
iv. How else has the injury affected you financially?

   - Household income

3. General
i. What are other problems relating to the injury which affect your life currently?
ii. How do you feel your life has changed since the injury? How has the injury affected you overall?
iii. How do you think that the challenges you described because of the injury could be reduced or improved?
You are being invited to participate in a research study. Before you take part in this research study, the study must be explained to you and you must be given the chance to ask questions. Please read carefully the information provided here. If you agree to participate, please sign the informed consent form. You will be given a copy of this document to take home with you.

Title: Socio-economic and Quality of Life outcomes in post-discharge trauma patients in urban India

PURPOSE OF THE RESEARCH STUDY

We are currently conducting research in this hospital to study what are the social and economic challenges faced by patients who have had an injury after discharge. We ask you to participate in this study because you presented to this hospital after having an injury.

STUDY PROCEDURES AND VISIT SCHEDULE

If you agree to participate, we will call you or a relative three months (90 days) after you arrived to this hospital to hear how you are. We will ask you in the call permission to visit you at your home. If you agree we will visit you at a time convenient to you to talk to you about health after discharge. You do not have to answer certain questions if you prefer not to. You can also end the interview whenever you want, even if all questions have not been answered. An audio recording of the interview may be taken.

WITHDRAWAL FROM STUDY

Participation in this study is completely voluntary. Even if you agree to participate now you are free to withdraw at any time without giving any reason for doing so. Withdrawing will not affect your ordinary treatment or the care given to you. To withdraw you contact any of the study contact persons on the numbers or emails listed below.

POSSIBLE RISKS, DISCOMFORTS AND INCONVENIENCES

We have not been able to identify any major risks associated with participating in this study. If you would at that point, or any other point of time, wish to withdraw from the study, you are free to do so.

POTENTIAL BENEFITS

Our research may help to study the different social and economic problems faced by patients like you after discharge. Although this research will not affect the care you are given in this hospital at this time, its results might help you if you are injured again in the future, or others that are injured. There is no assurance you will benefit from this study. However, your participation may contribute to the medical knowledge about the use of this intervention.

SUBJECT’S RIGHTS

Your participation in this study is entirely voluntary. Your questions will be answered clearly and to your satisfaction. In the event of any new information becoming available that may be relevant to your willingness to continue in this study, you will be informed in a timely manner by the Principal Investigator or his/her representative.
CONFIDENTIALITY OF STUDY AND MEDICAL RECORDS

The results of this research may be published as a scientific article; however, it will not be possible to identify you by reading any article that may result from this work. Further, data from this project will be shared with other researchers in India and abroad, but it will not be possible to identify you using only that data.

COSTS OF PARTICIPATION

If you take part in this study, there will be no charge levied on you. You will not receive any compensation for participating in this study.

RESEARCH RELATED INJURY AND COMPENSATION

The study being observational is not likely to cause any research related injury.

WHO TO CONTACT IF YOU HAVE QUESTIONS

If you have questions about this research study and your rights or in the case of any injuries during the course of this study, you may contact:

Principal Investigator:
Co-Investigator:
Institutional Ethics Committee:
TRIAGE STUDY (TTRIS)

We are currently conducting research to study tools to help doctors and nurses to early identify injured patients that need to be seen soon after they arrive to hospital. We ask you to participate in this study because you present to this hospital after sustaining an injury. To carry out this research we would need to contact you or your relatives once you get home to inquire about your status. We will do so by calling you or one of your relatives that you decide at three occasions. The first time will be one day after you arrived to this hospital. The second time will be one month after you arrived to this hospital. The third and final time will be you six months after you arrived to this hospital. After six months, we will conduct a short telephone interview and ask you about your health status.

1. Benefits of participating in this study

Our research may help to find tools that better identify injured patients in need of immediate care. Although this research will not affect the care you are given in this hospital at this time, its results might help you if you are injured again in the future, or others that are injured.

2. Risks associated with participating in this study

We have not been able to identify any major risks associated with participating in this study. You may experience some degree of discomfort when we contact you over phone. If you would at that point, or any other point of time, wish to withdraw from the study, you are of course free to do so.

3. What it means to participate

If you agree to participate, we will:

- Call you or a relative one day after you arrived to this hospital to hear how you are. If you are still in hospital, we will visit you in the ward.
- Call you or a relative 30 days after you arrived to this hospital to hear how you are. If you are still in hospital, we will visit you in the ward.
- Call you or a relative six months after you arrived to this hospital. We will then conduct a short interview, lasting less than five minutes, to find out about your health status.

When you arrived to hospital, we recorded some basic parameters such as your age, gender, and how you were injured. If you want to be informed about all the parameters that were recorded, please do ask and we will be happy to inform you. If you wish that your information is deleted from the study you may tell us now or contact us later on using the contact information provided below. The results of this research may be published as a scientific
article; however, it will not be possible to identify you by reading any article that may result from this work.

4. Withdrawal of participation

Participation in this study is completely voluntary. Even if you agree to participate now you are free to withdraw at any time without giving any reason for doing so. Withdrawing will not affect your ordinary treatment or the care given to you. To withdraw you contact any of the study contact persons on the numbers or emails listed below.

Principal Investigator:
Co-Investigator:
Institutional Ethics Committee:
15 APPENDIX 4: PATIENT INFORMATION SHEET TRAUMA AUDIT FILTER TRIAL (PAPER IV)

PATIENT INFORMATION SHEET

You are being invited to participate in a research study. Before you take part in this research study, the study must be explained to you and you must be given the chance to ask questions. Please read carefully the information provided here. If you agree to participate, please sign the informed consent form. You will be given a copy of this document to take home with you.

Title: The Trauma Audit Filters Trial

PURPOSE OF THE RESEARCH STUDY

We are currently conducting research in this hospital to study if implementing a structured approach to measuring and acting on care quality data may improve care and outcomes of patients with injury. We ask you to participate in this study because you present to this hospital after having an injury.

STUDY PROCEDURES AND VISIT SCHEDULE

If you agree to participate we will:

1. Call you or a relative one day after you arrived to this hospital to hear how you are. If you are still in hospital we will visit you in the ward.

2. Call you or a relative 30 days after you arrived to this hospital to hear how you are. If you are still in hospital, we will visit you in the ward.

3. Call you or a relative three months (90 days) after you arrived to this hospital to hear how you are. If you are still in hospital, we will visit you in the ward. At this time, we will also conduct a short interview, lasting less than five minutes, to find out about your health after being discharged.

When you arrived to hospital, we recorded some basic parameters such as your age, gender, and how you were injured. If you want to be informed about all the parameters that were recorded, please do ask and we will be happy to inform you. If you wish that your information is deleted from the study you may tell us now or contact us later on using the contact information provided below. The results of this research may be published as a scientific article; however, it will not be possible to identify you by reading any article that may result from this work. Further, data from this project will be shared with other researchers in India and abroad, but it will not be possible to identify you using only that data. Research on that without identifiers may seek to answer other questions than those stated above.

WITHDRAWAL FROM STUDY

Participation in this study is completely voluntary. Even if you agree to participate now you are free to withdraw at any time without giving any reason for doing so. Withdrawing will not affect your ordinary treatment or the care given to you. To withdraw you contact any of the study contact persons on the numbers or emails listed below.

POSSIBLE RISKS, DISCOMFORTS AND INCONVENIENCES
We have not been able to identify any major risks associated with participating in this study. If you would at that point, or any other point of time, wish to withdraw from the study, you are free to do so.

**POTENTIAL BENEFITS**

Our research may help to find tools that better identify injured patients in need of immediate care. Although this research will not affect the care you are given in this hospital at this time, its results might help you if you are injured again in the future, or others that are injured. There is no assurance you will benefit from this study. However, your participation may contribute to the medical knowledge about the use of this intervention.

**SUBJECT’S RIGHTS**

Your participation in this study is entirely voluntary. Your questions will be answered clearly and to your satisfaction. In the event of any new information becoming available that may be relevant to your willingness to continue in this study, you will be informed in a timely manner by the Principal Investigator or his/her representative.

**CONFIDENTIALITY OF STUDY AND MEDICAL RECORDS**

The results of this research may be published as a scientific article; however, it will not be possible to identify you by reading any article that may result from this work. Further, data from this project will be shared with other researchers in India and abroad, but it will not be possible to identify you using only that data.

Research on that without identifiers may seek to answer other questions than those stated above. Also, Regulatory Agencies, Institution Review Board and Ministry of Health will be granted direct access to your original medical records to check study procedures and data, without making any of your information public. By signing the Informed Consent Form attached, you are authorizing such access to your study and medical records.

**COSTS OF PARTICIPATION**

If you take part in this study, there will be no charge levied on you. You will not receive any compensation for participating in this study.

**RESEARCH RELATED INJURY AND COMPENSATION**

The study being observational is not likely to cause any research related injury. However, hospital will provide adequate medical care for any problem/s arising during the study.

**WHO TO CONTACT IF YOU HAVE QUESTIONS**

If you have questions about this research study and your rights or in the case of any injuries during the course of this study, you may contact:

*Principal Investigator*

*Co – Investigator*

*Institutional Ethics Committee*