

**Scarf Injuries in Bangladesh: Exploring the Impact on Females who live with Spinal
Cord Injuries**

by

Anna Tupetz

Duke Global Health Institute

Duke University

Date: _____

Approved:

Dr. Catherine Staton, Supervisor

Dr. Mike Landry

Dr. Mary Story

Thesis submitted in partial fulfillment of
the requirements for the degree of
Master of Science in the Duke Global Health Institute
in the Graduate School of Duke University

2019

ABSTRACT

**Scarf Injuries in Bangladesh: Exploring the Impact on Females who live with Spinal
Cord Injuries**

by

Anna Tupetz
Duke Global Health Institute
Duke University

Date: _____

Approved:

Dr. Catherine Staton, Supervisor

Dr. Mike Landry

Dr. Mary Story

An abstract of a thesis submitted in partial
fulfillment of the requirements for the degree
of Master of Science in the Duke Global Health Institute
in the Graduate School of Duke University

2019

Copyright by
Anna Tupetz
2019

Abstract

Background: A growing number of female passengers of a newly-introduced battery powered taxi, referred to as the 'Easy Bike', sustained Spinal Cord Injuries and anterior neck lacerations. This severe injury occurs, as their traditional scarves entangle in the taxi's engine drive shaft. Injuries sustained by entanglements of scarves in machinery has been known in the literature as Scarf Injuries. This study aimed to conduct key informant interviews to explore Scarf injury survivors challenges in receiving adequate care and maintaining a high Quality of Life (QoL). Methods: We conducted semi-structured in-depth interviews with 12 Scarf Injury survivors and their caregivers after discharge from a rehabilitation center in Bangladesh. Results: The main themes that emerged from the qualitative data were 1) perceived level of health, function and possible participation, 2) access to emergency and acute care and quality of care, 3) challenges in community reintegration. Participants often perceived their ability to perform activities and tasks to be lower than their bodily functions allowed, leading to a self-limitation in their daily social life. Commonly reported health concerns were urinary and bladder control, infections and breathlessness. None of the participants perceived that they received appropriate emergency care at the injury site, and transportation to a medical facility usually occurred in unsafe vehicles due to limitations in general awareness and knowledge of the injury sustained. At the facilities there was a reported gap in knowledge and competencies regarding the etiology of this type of SCI, leading to multiple referrals for diagnosis and delayed management. Community and social

reintegration was mainly impacted by lack of financial resources, lack of realistic goals, poor mental health including suicidal thoughts and previously mentioned secondary complications.

Conclusions: Increasing awareness and knowledge about SCI emergency and acute care might contribute to improved long-term clinical outcomes and survival rates among Scarf Injury survivors. Moreover, greater competencies and awareness among providers to manage this unique mechanism of injury would increase the patient's and caregiver's level of understanding of their condition, and would result in earlier adoption of a coping process.

Implications: Early rehabilitation that focuses on physical and mental health, alongside empowerment and integration, appears to be lacking in this setting. Further studies are needed to identify effective and culturally sensitive intervention programs for females living with Scarf Injuries in LMICs.

Dedication

I dedicate this research project to my mother, who has taught me to work hard and follow my dreams. She has made it possible for me to go on this journey and I will be forever grateful for your support and love.

Contents

| | |
|---|----|
| Abstract | iv |
| Dedication | vi |
| List of Tables | ix |
| List of Figures | x |
| Acknowledgements | xi |
| 1. Introduction | 1 |
| 1.1 Background | 1 |
| 1.2 Rationale | 13 |
| 1.3 Aims | 14 |
| 2. Methods | 15 |
| 2.1 Setting | 15 |
| 2.2 Participants | 17 |
| 2.3 Procedures | 18 |
| 2.4 Measures/ Interview Guide | 22 |
| 2.5 Analysis | 23 |
| 2.6 Conceptual and Theoretical Frameworks | 28 |
| 3. Results | 32 |
| 3.1 Description of Injury, Emergency Response, Access to Care | 36 |
| 3.2 Presentation of Scarf Injuries, International Classification of Functioning, Disability and Health | 41 |

| | |
|--|-----|
| 3.3 Challenges and Facilitators for Community Reintegration, Future Needs and Perspectives | 68 |
| 4. Discussion | 87 |
| 4.1 Implications for Policy and Practice..... | 93 |
| 4.2 Implications for Further Research | 96 |
| 4.3 Study Strengths and Limitations | 98 |
| 5. Conclusion | 100 |
| Appendix A: Photographs..... | 101 |
| References | 103 |

List of Tables

| | |
|--|----|
| Table 1: Structure of Interview Guides | 23 |
| Table 2: Theoretical Frameworks Overview, Bioecological Model..... | 28 |
| Table 3: Characteristics of Scarf Injury Population | 34 |

List of Figures

| | |
|--|----|
| Figure 1: Coding Tree, Aim 1&2 | 26 |
| Figure 2: Coding Tree, Aim 3 | 27 |
| Figure 3: Flowchart of Participant Selection | 33 |
| Figure 4: Overview of Scarf Injury ICF Model..... | 41 |
| Figure 5: Biopsychosocial Model | 54 |
| Figure 6: Bioecological Model | 69 |

Acknowledgements

I would like to thank the research team and our colleagues in Bangladesh at CRP, who worked tirelessly to conduct this study. Their commitment to serving the people in need was inspiring. Additionally I'd like to thank my professors here at the Duke University who supported me throughout the process.

1. Introduction

This study examines the impact of a highly disabling if not fatal type of traffic injury in Bangladesh, that almost exclusively affects young females. In this introduction section, we will provide a full review of the relevant literature.

1.1 Background

Road Traffic Injuries in Low and Middle Income Countries (LMICs)

With increasing urbanization in LMIC, traffic injuries are rising, threatening to become the seventh leading cause of death by 2030 and already are considered to be the leading cause of death for children and youth between 15 and 29 years of age, globally. WHO estimates that 93% of all fatal road injuries occur in low and middle income countries, despite the fact that those countries only account for approximately 60% of vehicles globally. (WHO, 2012)

Scarf Injuries and Easy Bikes

In recent years, there has been an increased incidence of patients presenting at the Centre for the Rehabilitation of the Paralyzed (CRP) (Savar, Bangladesh) with traumatic Spinal Cord Injuries (SCI) resulting from a Scarf Injury (CRP-Bangladesh, 2013-2018). A Scarf Injury is caused by unintentional entanglement of the traditional scarves worn in

many Asian countries, within some form of machinery, resulting in Spinal Cord Injuries (SCI).

Further investigation by CRP staff revealed, that the majority of those individuals admitted were caused by a newly introduced auto-rickshaw, called the Easy Bike. Easy Bikes are three-wheeled auto rickshaws, that have gained popularity in Bangladesh, due to its cost effectiveness, as they are battery powered and are therefore not impacted by the rising fuel prices in Bangladesh. (Mallik & Arefin, 2018)

Easy Bikes have been publicly discussed after its immense rise in numbers on the roads over the past years, there is a corresponding increased burden on the electricity network in Bangladesh. Nevertheless, this debate has not decreased their popularity amongst the general population. Easy Bikes are a very popular mode of transportation. They are popular among drivers, as a relatively cheap investment to provide an income for their families, as well as the passengers, due to their lower transportation fees compared to other taxis. Therefore, Easy Bikes are most commonly used by those with lower incomes and students. (CRP, 2018; Moniruzzaman, 2016)

It was estimate in 2016 that, 18,000 families were surviving financially by the operation of 20,000 Easy Bikes in Khulna. (Moniruzzaman, 2016) However, those numbers are expected to be highly underestimated, as no license and official registration is required to obtain such vehicle.

It has since been reported by our colleagues in Bangladesh, that the Easy Bikes have been banned from urban areas, due to their high contribution in traffic jams and limited speeds compared to other vehicles on the roads. Easy Bikes are now seen widely in semi-urban and rural areas, and continue to be the main mode of transportation and commute for many low income citizens and students. We have been told, that the Easy Bikes are said to be predominantly imported from China, yet assembled in Bangladesh. (CRP, 2018) In China, Easy Bikes are widely used as mode of transportation, however there they do not pose significant injury risks, as the Chinese female population is not wearing long scarves as part of their traditional clothing. (CRP, 2018) There are several models of Easy Bikes that can be purchased online. The cheapest model, that we could find online is the Easy Bike that we have seen almost exclusively being driven in Bangladesh. (Alibaba.com, 2019)

Image 1 shows a typical example of the Easy Bike, that is being used in Bangladesh. There is a gap between the driver and the passenger seat, with the drive shaft directly beneath that gap. When any type of cloth gets into that gap, it can get entangled in the drive shaft and forcefully suck the object into the shaft.

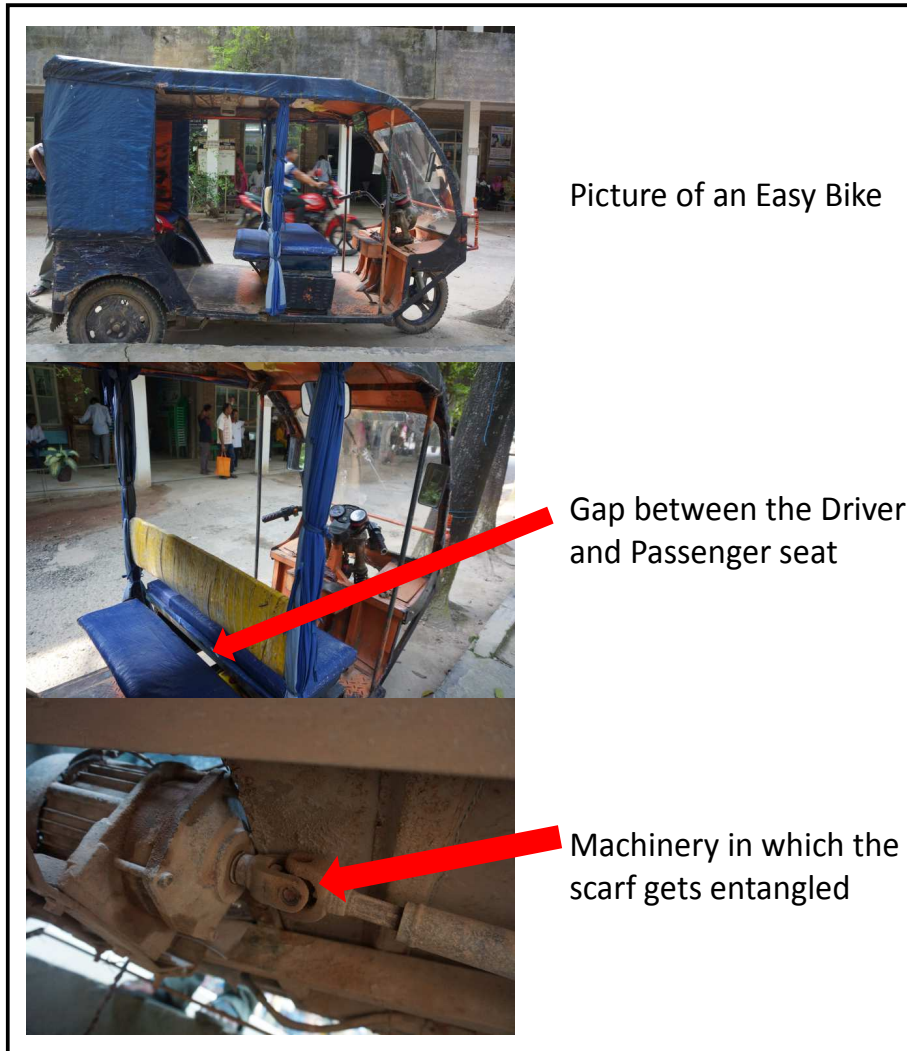


Image 1: Example of the Easy Bike

Scarf Injuries were first mentioned in the early 1970's in North America, resulting from entanglements in machineries, such as snow mobiles or ski lifts. (Habal, Meguid, & Murray, 1972; Meguid & Gifford, 1972)

Jain et al. were the first to also report vehicle related SCI from Scarf Injuries in India in 2008, where 4 out of the 12 reported cases suffered a Scarf Injury from being a passenger on a motorbike or cycle rickshaw. (Jain et al., 2008) All 12 cases in the Jain et al study, showed no form of recovery and the majority reported temporary unconsciousness after the event. Following up from their first report, a few single case reports have been published on the broader topic of Scarf Injuries involving certain types of vehicles (Agrawal, Ninave, Srivastava, Sunkara, & Agrawal, 2009; Mugadlimath, Sane, Kallur, & Patil, 2013; Tumram & Ambade, 2013) Singh et al. (2017) performed a hospital-based prospective observational study, recording the demographic profile, mode of trauma, contributing factors, injury pattern and early management including early complications of scarf-related injuries. Out of the 76 patients, 46% acquired the injury due to scarf entanglements in the spoke wheels of vehicles. (P. Singh, Kumar, & Shekhawat, 2017)

To our knowledge, there is literature reporting Scarf Injuries while being a passenger in a taxi as we have found in the clinical cases presenting to CRP. In this specific case in Bangladesh, the scarf becomes entangled in the drive shaft of the taxi, and not in the vehicle's wheel as previously presented. This specific mechanism of injury may result in greater degree of cervical spine dislocation and strangulation, due to the inability of the passenger to dislodge themselves following the scarf entanglement.

Scarf Injuries and Road Traffic Injury (RTI)

While not a 'traditional' Road Traffic Injury (RTI), as it does not involve a vehicle crash, but an injury that occurs within that mode of transportation, we argue to still consider this type of Scarf Injuries by the Easy Bike an RTI.

This injury can be even more easily prevented as a vehicle crash, as the only action to take is, to make the vehicle safe, regardless of road and traffic conditions. The WHO lists common risk factors for RTI including unsafe vehicles, and calls for regulations on vehicle safety to protect 'those in the vehicle and those out of it'. (WHO, 2012) In addition to that, another risk factor mentioned by the WHO is inadequate post-crash care, increasing the risk of poorer health outcomes, such as death or increased disability. (Peden et al., 2004)

Disability in Low and Middle Income Countries (LMICs)

Not only are RTI the leading cause of death in young adults ranging from 15-29 years, they are also accountable for 20-50 million injuries per year, many of which result in a disability. (Peden et al., 2004) According to the World Bank, life expectancy in Bangladesh has steadily increased over the past decades, as have most other LMIC life expectancy trends. Despite the increased incidence, the death rate has simultaneously been decreasing over time, based on trends until 2016. (Worldbank, 2019)

Those developments can likely be attributed to better access to healthcare and improved medical services. However, alongside increasing survival rates, disability has also increased. Low and Middle Income Countries are believed to account for 91.8% of DALYs lost due to RTIs globally. (Peden et al., 2004)

People living with disability account for an estimated 15% of the world's population, or 1 billion people globally.

Over the past decades disability has gained more public attention and the awareness of a growing need to not only decrease mortality worldwide, but to focus on those who survive illness and injuries, yet become disabled. Disability is considered to be both, a Human Rights, as well a Developmental issue. (Bickenbach, 2011) In 2006, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) formulated its convention's purpose as to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." (UN, 2008)

In addition to that, the experience of disability can greatly vary based on environmental and contextual factors, which is why the WHO developed the International Classification of Functioning and Disability. (WHO, 2014) In LMICs, contextual factors, such as accessible homes, provision of assistive devices, access to ongoing rehabilitation treatments, and social integration are often more difficult to ensure than in developed countries with the necessary resources and health systems in place. Cultural and gender

norms might greatly influence the way a person experiences their disability, possibly facing stigmatization, social isolation or deprivation of education. Disability disproportionately is affecting vulnerable populations (poorest wealth quintile, women and increased age). (WHO, 2011)

Note, that Easy Bikes are most commonly used by people of low socioeconomic status. Additionally, Scarf Injuries almost exclusively affect females, due to cultural clothing norms. Therefore, Easy Bikes pose a direct risk for Disability for already vulnerable populations, as defined by the WHO.

The United Nations Economic and Social Commission for Asia and the Pacific (UN ESCAP) estimated the number of persons living with a disability to be around 650 million in the Asia Pacific region, acknowledging, that the majority of disabled people are living in poverty, are “disadvantaged and discriminated against”. (UN-ESCAP, 2012)

The Asian and Pacific Decade of Persons with Disabilities 2013-2022 , a continuation of the past decade 2002-2012, is an intergovernmental initiative and a 10 year regional strategy to create a society that is disability-inclusive. The new plan puts more emphasis on the integration of persons with disabilities, leading to governments and regions to already have implemented policies and legal measures to protect the rights of persons with disabilities. (UN-ESCAP, 2012)

Spinal Cord Injuries

As mentioned previously, to our knowledge this type of Scarf Injuries results in either fatal outcome, or a complete cervical Spinal Cord Injury. In the South-East Asia Region, an estimated 40% of SCI are attributed to RTI, followed by falls. Spinal Cord Injuries are according to WHO's World Report on Road Traffic Injury Prevention, alongside head injuries, the most costly injuries at 332,457 USD per injury. This amount exceeds the combined costs for all other injuries and fatalities. The estimated incidence is believed to be between 250,000 and 500,000 new cases each year. (Bickenbach, Officer, Shakespeare, von Groote, & WHO, 2013) Though we can see an increase in prevalence predominantly in high income countries, the relatively lower prevalence in LMICs is thought to be caused by lower survival rates. (WHO & ISCOS, 2013)

Based on a five year observational study, performed by CRP, the only Spinal Cord Injury Rehabilitation clinic in Bangladesh, a total of 2184 patients were admitted between January 2011 to January 2016. (Rahman et al., 2017)

However, we expect a lot of SCI survivors to have not had access to a rehabilitation facility and therefore the population wide prevalence to be significantly higher.

Out of those 2184 Spinal Cord Injury patients, 86.8% (n=1897) were male, a higher male to female ratio as suggested by global research, however current reviews are lacking data from LMIC and acknowledge high variations in male to female ratios across countries. (A. Singh, Tetreault, Kalsi-Ryan, Nouri, & Fehlings, 2014; WHO & ISCOS,

2013) The much higher male to female ratio presented by Rahman et al. , could be due to cultural gender norms, and may be depriving females from access to rehabilitation care.

When looking at the risk factors in the female population only, WHO estimates, that females between 15 and 19 and older age (60+) are most at risk for sustaining a SCI, globally. (WHO, 2013) Based on a hospital records from CRP on Scarf Injury patients, this trend is represented in the scarf injury population with 56% of patients being below 20 years of age. There were no Scarf Injury patients of older age (60+) admitted to CRP. This could be due to the fact, that either the Easy Bikes are mainly used by younger females, or that older injury victims might not be able to access CRP.

The hospital records of our collaborating Rehabilitation Centre indicate, that more than 60% of the admitted Scarf Injury patients were students at the time of injury.

A study conducted in Zimbabwe investigated life expectancy and the daily life of persons with SCI in low-resource settings. The study found, that pressure sores and urinary tract infections were the most common secondary complications, often leading to premature death. In addition to that, the authors discovered, that poverty increased barriers for successful management of the conditions, further increasing their risk of premature death. (Øderud, 2014)

Life Satisfaction and Mental Well-being in Spinal Cord Injury Patients in Low and Middle Income Countries

The WHO defines Mental Health as ‘... a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.’

(WHO, 2005)

It seems apparent, how suffering a traumatic injury and/or living with a chronic physical disability can negatively influence the mental health of the survivors, but also the immediate social network.

Road Traffic Injuries in general, and SCIs specifically, have a great psychosocial impact on the survivors and their families, by affecting all three of those contributing factors.

The family members of a SCI survivor are now faced with their loved one experiencing physical, social and psychological effects. (Peden et al., 2004)

In the long-term management of Spinal Cord Injuries, the prevention of secondary complications is a priority in decreasing morbidity and increasing community participation, thereby increasing the patient’s Health Related Quality of Life (QoL).

Common secondary health concerns include respiratory, cardiovascular, and bowel/bladder complications, pressure sores, pain syndromes as well as osteoporosis and bone fractures. (Sezer, Akkuş, & Uğurlu, 2015)

Managing a SCI often requires assistance for daily activities throughout their lifespan, financial resources to manage and prevent secondary complaints as well as a strong social support network to counteract the risk for decreased mental health. Those needs are often not met in developing countries and require special attention. (Burns & O'Connell, 2012)

It is not uncommon for SCI patients to suffer from depression, which can further influence the sense of social isolation, keeping them from returning to an empowered life in their community. (WHO & ISCOS, 2013)

A study of 134 SCI patients in Teheran showed, that 63% of female SCI patients showed signs of depression. Of all 134 participants, 76% of those with depression reported suicidal thoughts. (Khazaeipour, Taheri-Otaghsara, & Naghdi, 2015)

Van Leeuwen conducted a review on psychological issues in SCI, emphasizing the need for further research and focus on the subjective well-being of SCI patients, to enhance their Quality of Life. (van Leeuwen et al., 2012)

SCI patients living in LMIC are facing even higher barriers and challenges to overcome than patients living in HIC, in order to feel socially integrated. Therefore we can expect an ever lower life satisfaction in SCI populations living in low-resource settings, compared to those with better access and resources available.

1.2 Rationale

The overall purpose of this study was to explore the outcomes from Scarf Injuries and its impact on the survivors and their families.

Considering the extent to which this is an injury that, if not fatal, creates a significant degree of disability among the survivors, it is critical to gain a deeper understanding of the risk factors leading to this injury. Moreover, influencing factors contributing to the success of acute care delivery, as well as learning about the specific needs, barriers and challenges of survivors towards an independent and empowered life with this disability are crucial.

Once we understand this specific and new type of injury better, get to learn the Scarf Injury population and their environment better, we have the opportunity to have more targeted future prevention efforts, as well as long term rehabilitation programs, focusing on the transition of care after discharge from CRP. We believe that the qualitative data gathered through this study can be used to inform interventions for the larger population of females living with disabilities in LMIC.

1.3 Aims

1. Describe the level of perceived and clinical functioning (observed during interview, and based on clinical health records) in Scarf Injury Survivors, using the International Classification of Functioning, Disability and Health
2. Develop a qualitative description of the experiences of the mechanism of injury as well as acute care received by the survivors and caregiver's perspectives.
3. Identify the needs and barriers for personal functioning and community reintegration from the perspective of Scarf Injury survivors and their caregivers

2. Methods

This study presents a qualitative study, based on phenomenological methods. A qualitative approach was well suited to the study objectives, because it allowed a deeper insight into the experiences of Scarf Injury survivors and their families, including the interaction between the injury and the rehabilitation process, as well as the coping responses of the patients and their caregivers. The study included 18 semi-structured in-depth interviews with Scarf Injury survivors and their respective caregivers in their home-setting, visiting 12 families. Even though we visited 12 families, not in all cases the caregivers were interviewed separately, therefore we have a total of 18 interviews instead of 24. Study participants were selected from a facility based registry of Scarf Injury patients admitted to a single Rehabilitation Centre between 2013 and 2018.

2.1 Setting

The Centre for the Rehabilitation of the Paralysed (CRP), is a multi-centered medical facility, with a total of 12 locations throughout Bangladesh, that provides medical and rehabilitation services, predominantly for neurological disorders. CRP Savar, the main office of CRP, provides in-patient care and rehabilitation services for Spinal Cord Injury Patients and is home to the Bangladesh Health Professions Institute. (CRP, n/a)

Description of the Research Team

The research team in Bangladesh was led by a English-speaking female Physiotherapist, affiliated with the Duke Global Health Institute, who was trained in qualitative research methods and conducted the interviews with the participants. This researcher was also the main analyst of the collected data. She was supported by a female translator from Bangladesh, fluent in English and Bangla, who also was a trained Physiotherapist. The translator was not employed by CRP and was therefore not known by the participants. Two research assistants, both physiotherapists at CRP, who could have been known by the patients, assisted in the recruitment of participants, logistics of the home visits, revision of the interview guides, training of the translator and continuous feedback on interview procedures and cultural appropriateness during the data collection period. Given their role at CRP, these individuals were not involved in the data collection and only had access to data after it was de-identified, to protect the participant's privacy during the interviews. The study team also had access to a trained psychologist at CRP, who was known by all patient participants, to consult in the case of urgent psychological support of the study participants.

2.2 Participants

The interviews were conducted with female Scarf Injury patients (Group A) and their caregivers (Group B). In order to identify our study population, we used a dataset of admitted patients from the rehabilitation center and created a list of possible study participants that fit our eligibility criteria. This dataset also served as additional source of demographic patient information to compliment the qualitative data.

Eligible participants for this qualitative study were selected based on the following eligibility criteria for the Scarf Injury patients:

- Former patient at the Rehabilitation Centre, treated for Scarf Injury caused by being a passenger in the Easy Bike between 2014 and 2018;
- Diagnosis complete or incomplete cervical SCI
- Living with at least one caregiver;
- Discharge from the Rehabilitation Centre at least 3 months prior to potential interview;
- Communicating in Bengali/Bangla;
- Not younger than 10 years of age at the time of the injury.

We excluded those cases, that suffered a SCI that was not caused by a scarf strangulation, as well as patients with cognitive disability prior to, or caused by the injury.

After we identified the patients' eligibility for the study, we assessed the eligibility to participate of their family members, serving as caregivers (Group B). We only enrolled family members of already identified possible patient participants (Group A). In order to interview the caregivers of the patients, we included only those who are the primary caregiver of the patient, lived in the same house and was involved in the care and daily activities of the patient. We excluded those, who were the Legal Guardian of the patient, but not the primary caretaker.

2.3 Procedures

Recruitment and Sampling Strategy

The study was introduced over the phone to all Scarf Injury patients by one of the research assistants, who was not involved in the data collection and analysis process but who may be known by the patients due to their employment at CRP. The CRP healthcare professional followed the same script for each phone call, which described the details of the study. This script also clearly stated, that whether they decide to participate or not will not have any implication on their relationship with CRP and further rehabilitation processes. The CRP healthcare professional who approached the prospective participants was asked to complete a form for initial contact, certifying that he/she contacted the subjects as written in the script which indicated whether the Scarf

Injury patient is willing to participate or decline. In the case of participants under the age of 18, we asked to talk to the patient to get assent, after having first received consent from their legal guardian.

After the Scarf Injury survivor (Group A) had expressed interest in participating, we then extended an invitation to participate to their respected caregivers (Group B), the same way we have approached Group A participants. For the caregivers to be asked to participate, the patient (Group A) had to agree to participate first. We did not include any caregivers that were not directly related to our patient sample, since we were interested in learning about the interactions and challenges within each family.

Therefore it was important to only include the caregivers, directly related to one

If the legal guardian, who had to give consent for the below 18 year old patients, was not the primary caregiver, the CRP healthcare professional also introduced the study to the primary caregiver and asked for their interest in participating in the study. After we identified our possible study population (n=24), we started to select participants for the interviews with the goal to include families that would represent a wide range of characteristics in terms of age at injury, time since injury, level and severity of injury, as well as profession and geographic location of residence and injury. We have gathered those information from the dataset that we also used to identify our sample population.

The attempted maximum variation sample was influenced by logistical challenges to reach the participants in their home-setting. We targeted to interview between 10-15

patients and their caregivers. We mapped the participant's location and started to schedule home visits with 15 families, that were feasible to visit, yet maintaining as best possible a representative sample of the Scarf Injury population.

Ethics

Ethical Approval was obtained from Duke Health Institutional Review Board, Protocol ID: Pro00092024, as well as CRP Ethics Committee, Bangladesh, Protocol ID: CRP-R&E-0401-224. Written or audio-recorded verbal consent was obtained from all participants. In case of under-age participants, assent was obtained from the children and informed consent was given by the legal guardian. All interviews were de-identified and assigned unique case IDs. Demographic information from the hospital records were transformed to be un-identifiable. We did not record any specific dates, locations or names. If the participants during the interviews mentioned specific names, we replaced those with Aliases.

Data Collection

About one week to 3 days prior the scheduled interview, we confirmed availability and willingness to participate in the study with the participants.

The interviews were conducted in the participant's home in July 2018, across different parts of Bangladesh. Home visits were chosen, to get an impression of the living

conditions and dynamics within the community, as well as the quantitative data that was collected during 2014 and 2018 at CRP. A maximum of two visits per day were scheduled, to ensure that sufficient time with each family could be spent, to build rapport, observe the family dynamics, as well as allowing time for questions and concerns from the participant's side. Informed consent was obtained by all participants at the day of the interview. Each visit lasted between 2 and 4 hours. The patient participants (Group A) had the option to decide whether caregivers and family members were present during the interviews. During the semi-structured interviews of Groups A and B, the researcher asked the questions in English, which was then synchronously translated into Bengali, the local language of the participants. The participant responses were then translated from Bengali back to English.

The recording of the first patient interview was evaluated and discussed with the research team. Based on the discussion and feedback from the research team, we performed another training session with the translator and provided her feedback, while listening to the recordings with her. Feedback by the research team was used to adjust the wording of some questions as well as implementing slight changes in the interview structure.

All interviews were digitally audio recorded and the audio recordings were transcribed in English. In order to assess whether we reached thematic saturation, we discussed the fieldnotes after each interview and identified the main topics and information covered in

each interview. After 10 home visits, the research team determined that no new themes were emerging. After an additional two interviews, we confirmed that thematic saturation was reached, and that our sample was a good representation of our sample population.

2.4 Measures/ Interview Guide

Based on the above mentioned study aims, we created separate interview guides for the patient and caregiver groups. The guide was developed by the head researcher and revised in several feedback rounds with qualitative experts from Duke University, as well as researchers and clinicians in Bangladesh, to ensure cultural appropriateness and relevance of questions.

The interview guides for the Group A and B were roughly divided into four parts as shown in Table 1 below. The difference between caregiver and patient interviews was, the caregiver interviews were intended to identify the perceived challenges of being a caregiver. The guide was structured first introducing the goal of the study again, and asking several opening questions to allow the participants to introduce themselves. Throughout the interview, mostly open-ended questions were used, allowing space for narratives of the participants to share their lived experiences, supplemented by probes, as well as follow-up questions if needed.

The questions focusing on the life after the injury and discharge, needs and challenges in community reintegration were influenced by the 6 broad WHO QoL domains (Physical Health, Psychological, Level of Independence, Social Relations, Environment, Spirituality/Religion/Personal Beliefs). (Whoqol-Group, 1998)

Table 1: Structure of Interview Guides

| Topic | Description |
|---|--|
| Introduction and demographics | living situation, family members, first insight in current level of activities and participation |
| Reconstruction of the event and access/delivery of immediate care | mechanism of injury, clinical outcomes, access to care, experiences of the medical care received until discharge |
| Life after the injury and discharge | daily life, challenges of living with a disability, Biopsychosocial model, QoL domains |
| Identification of needs to regain (disability adjusted) independence, adjustments, future goals | coping mechanisms and influencing factors for community re-integration, advice for other Scarf Injury patients or caregivers of Scarf Injury patients respectively |

2.5 Analysis

In order to ensure high quality and accuracy of the participants' responses, we decided to not transcribe the translated English versions of the participants' responses, provided

by the translator during the home-visits. An independent translator translated the participants responses from Bangla to English and transcribed the English versions.

All complete English transcripts were then proofread by an independent but experienced researcher, fluent in Bangla and English.

The questions and comments of the main researcher in English were included in the transcript. In the case of inconsistencies between the English version of the question and the wording the translator during the interview used, the transcripts were corrected by the independent researcher.

After transcription, we started the analysis process, using a content driven approach. We first split each interview broadly into our study aims (Mechanism of Injury & Access to care; Range of clinical outcomes; Daily life, Long-term rehabilitation needs). The codebook was then created through a lumping and splitting process and revised and discussed with peer researchers throughout the analysis process. 3 different interview sets (patient and caregiver) were then used to identify emerging codes from the transcripts. Throughout the creation of the code book as well as the coding process, peer feedback from researchers, not involved in the data collection was obtained at various stages.

The coding was performed by the same researcher, **who** also conducted the interviews.

An inter-rater-reliability approach with an independent researcher, who was not

involved in this project, was conducted with 3 of the 18 interviews, to compare the coding strategies and discuss the codebook.

Figure 1 presents the coding tree for each of the 3 aims of this research project. After the coding, analytic memos on Parent codes, were written and shared with the research team. The coding process was performed using NVivo12.

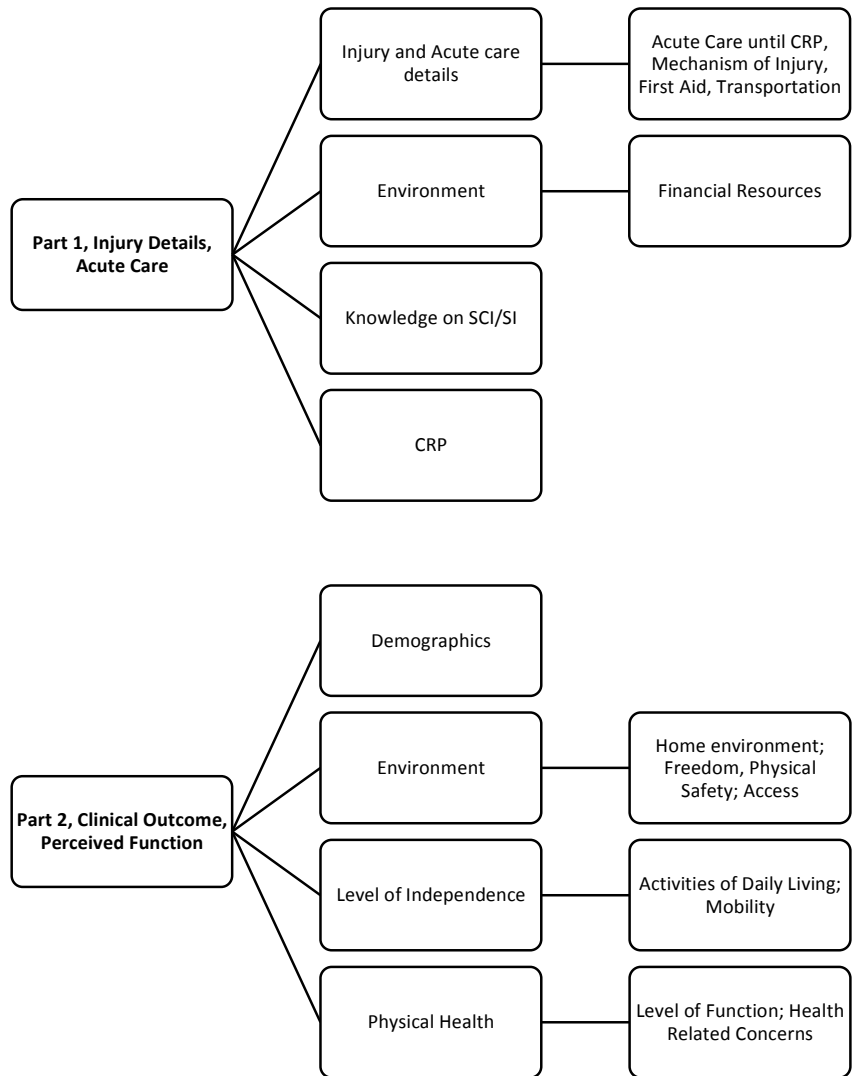


Figure 1: Coding Tree, Aim 1&2

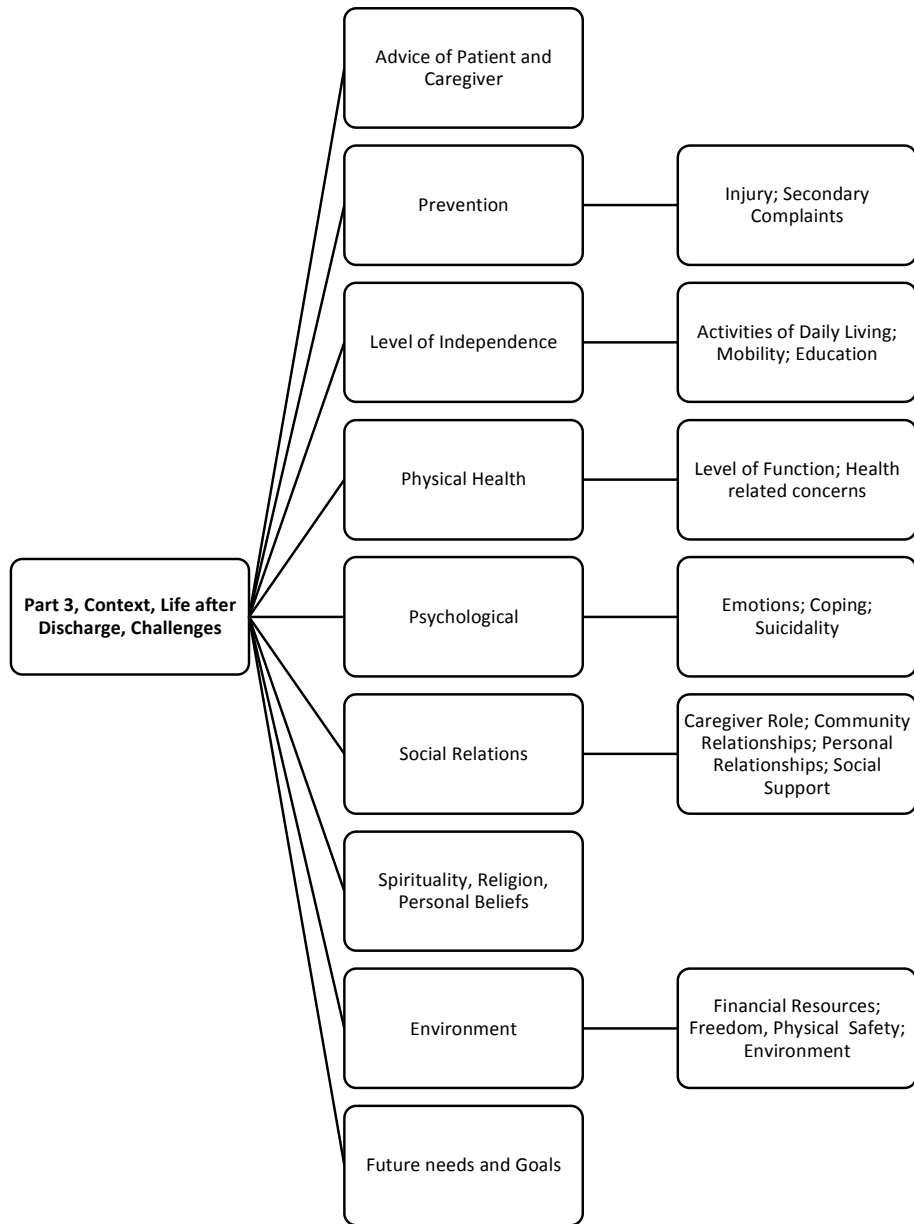


Figure 2: Coding Tree, Aim 3


2.6 Conceptual and Theoretical Frameworks

This section will provide an overview how the results will be structured and what theoretical frameworks will be utilized to conceptualize our findings.

We have primarily used the Bioecological Model of Bronfenbrenner, to present the results. (Bronfenbrenner, 1994)

The Model allows us to look into opportunities for future interventions from a variety of different angles, instead of solely focusing on the individual Scarf Injury survivor itself.

Table 2: Theoretical Frameworks Overview, Bioecological Model

| <u>Chronological</u>  | | | |
|---|--|---|--|
| <u>Components</u> | Process | Individual | Environmental/ Context |
| <u>Description</u> | Injury Details, Acute Care | Health Outcomes | Life after Discharge, Challenges |
| | Mechanism of Injury, First Aid, Acute Care, Transportation, Financial Burden | <u>ICF</u> (Health Condition, Body Function and Structures, Activity, Participation, Contextual factors), <u>Biopsychosocial Model</u> (Individual, Direct Environment of the Individual) | <u>Bioecological Model</u> (Interrelations of direct environment; Society at large; Culture, Traditions, Beliefs; Changes over time) |

The Bioecological Model, has 4 components: **Time, Process, Individual, Context/Environment.**

Time will be the central point for our analysis, dividing the findings chronologically.

Part 1: Process, Injury Details & Acute Care

We will start with the Injury itself, that represents the process of the injury and acute care delivery (Part 1).

This section will focus on the mechanism of injury, as well as emergency and acute care management until reaching the Rehabilitation Centre. We will briefly describe the care received at the Rehabilitation Centre.

Part 2: Individual, Health Outcomes

We will then move forward to the exploration of the **Individual after the Injury** was sustained (Part 2). We will present the patient population, their range of clinical findings as well as the comparison of the range of perceived level of abilities with the level of function based on the severity of the injury. For this part, we will make use of the WHO developed International Classification of Functioning, Disability and Health (ICF model) as a conceptual framework.

This framework examines the health condition, by dividing the individual's impairments and restrictions into the domains of body structures and functions, activity and participation levels.

The ICF is based on the Biopsychosocial model, firstly introduced by Engel and George in 1977. (George & Engel, 1980), further integrating contextual factors into the assessment of the patients. Contextual factors are divided into Personal and Environmental factors in the model. Personal factors are described by the WHO as 'influences on functioning particular to the individual which are not represented elsewhere in ICF.' (WHO, 2014) The WHO defines the Environmental factors as 'The physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning'. (WHO, 2014) That addition to looking at the individual shifts the focus from the health condition itself to a more holistic view, incorporating other influencing factors on the individual's wellbeing. This section of the results represents the following parts of Bronfenbrenner's Bioecological model: Individual and direct environment of the individual. (Individual and Microsystem)

Part 3: Context, Life after Discharge & Challenges

In the third part of this analysis, we will continue chronologically and present the life of the Scarf Injury survivors after discharge, their challenges in community re-integration and future needs.

We will move even further out from the factors, that directly influence the Individual (Individual and Microsystem) towards broader **contextual factors and the environment**.

We here include the interrelations of the direct environment (Meosystem), the Society at

Large (Macrosystem); Culture, Traditions, Beliefs (Exosystem); as well as how some aspects presented in this paper can change over time (Chronosystem).

This part will also cover future needs and perspectives, as well advice and prevention strategies, as described by the scarf injury survivors and their caregivers.

3. Results

Figure 3 shows the recruitment process of participants for this study. A total sample of 45 Scarf Injury patients were admitted to the rehabilitation center between 2014 and 2018. Out of those 45 patients, 44 were female. The male was confirmed dead at the time of the recruitment process. We do not have information on the one male Scarf Injury patient and whether he suffered the injury by the Easy Bike or a different vehicle. Of those women suffered the Scarf Injury caused by the Easy Bike. 10 cases were confirmed dead at the time of the recruitment, 1 declined to participate and another eligible patient was already enrolled in a different study. 4 patients were lost to follow up. Out of the 24 eligible participants who agreed to participate, 12 home visits were conducted in July 2018, interviewing the Scarf Injury survivors and their caregivers.

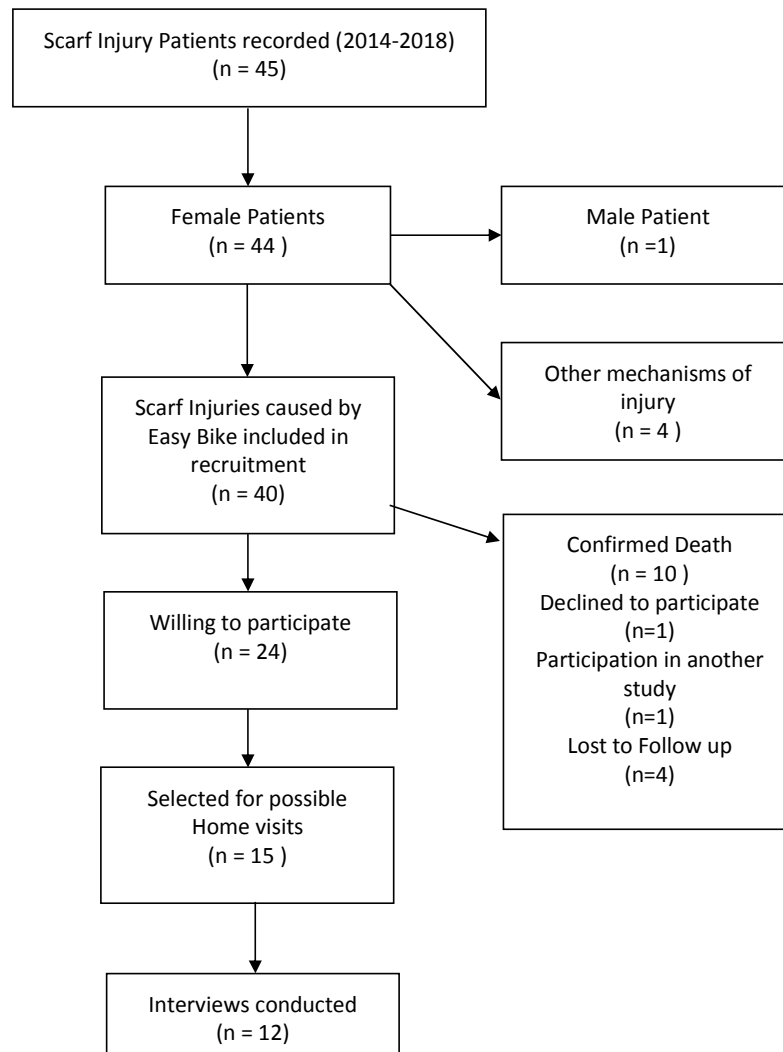


Figure 3: Flowchart of Participant Selection

Demographics

Table 3 presents the general characteristics of all admitted Scarf Injury patients (n=45) that were caused by the Easy Bike (n=40). All participants were discharged from the

rehabilitation center at least 4 months prior to the interview. The participants stayed on average 106 days in the rehabilitation center, with one participant leaving the center after one day up to a maximum of 187 days. One participant discharged herself after one day at her own risk, to receive surgery abroad. The majority of the participants was below the age of 20 at the time of injury and unmarried (57.5%). Two thirds of the sample population were students before the injury (62.5%).

Table 3: Characteristics of Scarf Injury Population

| | Female Scarf Injury total sample (admitted between 2014 and 2018) | Qualitative Sample |
|--------------------------------------|--|---------------------------|
| | (frequency/percentage) | (frequency/percentage) |
| | N=40 | N=12 |
| | N (%) | N (%) |
| Age (yrs) (at time of injury) | | |
| <10 | 0 | 0 |
| 10-15 | 17(42.5%) | 4 (33.3%) |
| 16-20 | 6 (15.0%) | 4 (33.3%) |
| 21-25 | 2 (5.0%) | 0 |
| 26-30 | 9 (22.5%) | 2 (16.6%) |
| 31-35 | 6 (15.0%) | 2 (16.6%) |
| 36+ | 0 | 0 |
| Marital Status | | |

| | | | |
|---|-----------------------------------|-----------------------|-------------|
| Married | 17 (42.5%) | 4 (33.3%) | |
| (Widowed, separated, husband married second wife) | No information | prior injury | post injury |
| | | 1 (8.3%) (widowed) | 2 (16.7%) |
| Unmarried | 23 (57.5%) | 8 (66.6%) | |
| Occupation | Prior injury (no f/u information) | prior injury | post injury |
| Student | 25 (62.5%) | 8 (66.6%) | 3 (25.0%) |
| Housewife | 11 (27.5%) | 3 (25.0%) | 0 |
| Teacher | 1 (2.5%) | 0 | 0 |
| Garment worker | 2 (5.0%) | 0 | 0 |
| Other | 1 (2.5%) | 1 (8.3%) | 1 (8.3%) |
| Place of Residence | | | |
| Urban | 14 (35.0%) | 1.5 (12.5%)* | |
| Semi-urban | 3 (7.5%) | 5 (41.6%) | |
| Rural | 23 (57.5%) | 5.5 (45.8%)* | |
| Diagnosis | | | |
| Paraplegic | 0 (0.0%) | | |
| Tetraplegic | 40 (100.0%) | 12 (100.0%) | |
| ASIA Score at time of admission to CRP | | | |
| A (complete) | 31 (77.5%) | 10 (83.3%) | |
| B (incomplete) | 5 (12.5%) | | |

| | | |
|--|-------------|--------------|
| C (incomplete) | 2 (5.0%) | 1 (8.3%) |
| D (incomplete) | 2 (5.0%) | 1 (8.3%) |
| E (normal) | 0 (0.0%) | |
| Surgery performed (N=39) | | |
| Yes | 18 (46.15%) | 5 (41.6%) |
| No | 21 (53.85%) | 7 (58.3%) |
| Length of Rehabilitation in days (Mean (Min,Max)) | 97 (1; 187) | 106 (1; 187) |
| Time to admission at Rehabilitation Centre in days post injury (Mean (Min,Max)) | 61 (0; 347) | 48 (1; 215) |

*(one participant commutes between family members)

3.1 Description of Injury, Emergency Response, Access to Care

Mechanism of Injury

In all interviewed cases, the patients sat behind the driver, and were in most cases not alone in the car. Many reported to be on the way to or from some community activities with the family or friends. The scarf was usually worn with one end in the front, the other one in the back, or both ends in the back, however in that case secured on the dress with safety pins.

The participants reported an instant and forceful pull, often leading to falling on the ground of the Easy Bike. Some participants instantly lost consciousness.

First Aid

First responders were usually the family members or friends in the Easy Bike. Due to the loss of consciousness or inability to speak due to the strangulation, the participants were often unable to communicate that they sustained a neck injury and lost sensation in their limbs initially.

One patient participant received help from fire fighters, at the site of the event, who repositioned her rotated neck into neutral position. Her mother believes, that this attempt in first aid worsened her injury.

A8: After rescue, I regained my consciousness on car while taking to (closest larger city). My neck was rotated, my neck became bent.

B8: When she had the accident, her neck rotated on this side. When people from fire service were taking her, they made the neck straight. The bones are all broken. After that she regained consciousness.

Some respondents indicate that the first reaction of the bystanders was to sit them up again on their seat, causing another fall.

Only one case described, that she had the urge to have her neck protected and was able to communicate that. Some women were first brought to nearby houses, before seeking medical attention. In all cases, the participants were not treated in the first clinic that they visited. Reasons for the lack of care were the inability to treat SCI, the inability to diagnose the injury as a Spinal Cord Injury and thereby misinterpreting the severity of

the injury, or due to the belief that the participants were presenting with a failed suicide attempt due to the strangulation marks refusing treatment for suicide attempt survivors.

Acute Care

The time between the day of the injury until the patient participants were admitted to CRP ranged between 1 and 215 days, with an average of 48 days (Table 3).

The number of medical facilities visited until being admitted to CRP was as high as 6 in some cases. Some hospitals did not admit or even assess the participants, knowing they will not be able to provide appropriate care. One young female, who self-reportedly had to be on life support, visited and was rejected by 5 facilities before being treated with traction. She was discharged from that hospital without further instructions, claiming there was nothing else to do for her. The family was unable to find facilities who were willing to admit her, due to her reliance on life support (likely meaning oxygen).

One survivor was discharged from the first facility with medication to treat the strangulation and pain. She developed bedsores after 3 days at home and was in such severe pain, that the parents decided to get a second opinion. Traction or surgery was performed in the majority of the patients. Two patient participants reported that the traction apparatus attached to their skulls broke after several days of treatment on one side.

A5: Then they referred me to Dhaka medical. After staying 1 month and 17 days there, they gave me traction. The traction was applied for 21 days but on 14th day, the traction fallen on floor by being torn.

After the tearing doctor said that she needs to be operated. Then again MRI was done before operation. Then operation took place. After operation I stayed there for 12 or 13 days. Then they referred me to CRP.

(...) the traction unfastened from one side. Usually the traction is attached on both side. It was unfastened from one side. They putted excessive weight that's why it became unfasten.

All interviewed Scarf Injury patients, except one who was illegally brought to India for surgery, received the actual SCI treatment in Dhaka, the capital of Bangladesh. Depending on the location of the participants, the journey to Dhaka was long and strenuous. While in Dhaka, they sometimes were required to stay in hotels in between the different hospitals and treatment periods.

In general, there was a lack of understanding of the injury suffered in patients, caregivers and medical professionals. Some females mentioned that they only learned what type of injury they suffered after having been in traction already for several weeks, or upon admission at CRP. Until then they have not received any information about their medical condition. Some participants also mentioned, that the healthcare providers, usually in the first clinic they visited mistakenly viewed the neck lacerations as the main health condition, not investigating further for the far more severe underlying Spinal Cord Injury.

A3: ...(the family) took me to hospital. After going there, when I said about my paralysis, they weren't understood. They thought how this small accident could cause paralysis.

Additionally, there was reported little education about possible recovery or greater chances of staying paralyzed also after treatment.

Transportation

No case was transported from the injury site to a clinic in an ambulance. Mostly they were carried by someone, or were sat up in the Easy Bike and transported to the closest clinic. After visiting the first clinic, in the majority of cases, they were transported in ambulances.

Financial Burden

In order to pay for the acute medical treatment, the need to sell family assets or receiving external financial support was mentioned. Bribe payments were mentioned in one case for admission to a government hospital and once to cross national borders to get surgery. Costs mentioned prior admission to CRP included hospital bills, transportation, buying of medical supplies (traction apparatus), treatment of secondary complaints (eg. bed sores) and were reported to reach up to 5lakh BDT, equivalent to almost 6000 USD. Those estimates from the caregivers do not include the costs for ongoing treatment after discharge home and possible indirect costs.

3.2 Presentation of Scarf Injuries, International Classification of Functioning, Disability and Health

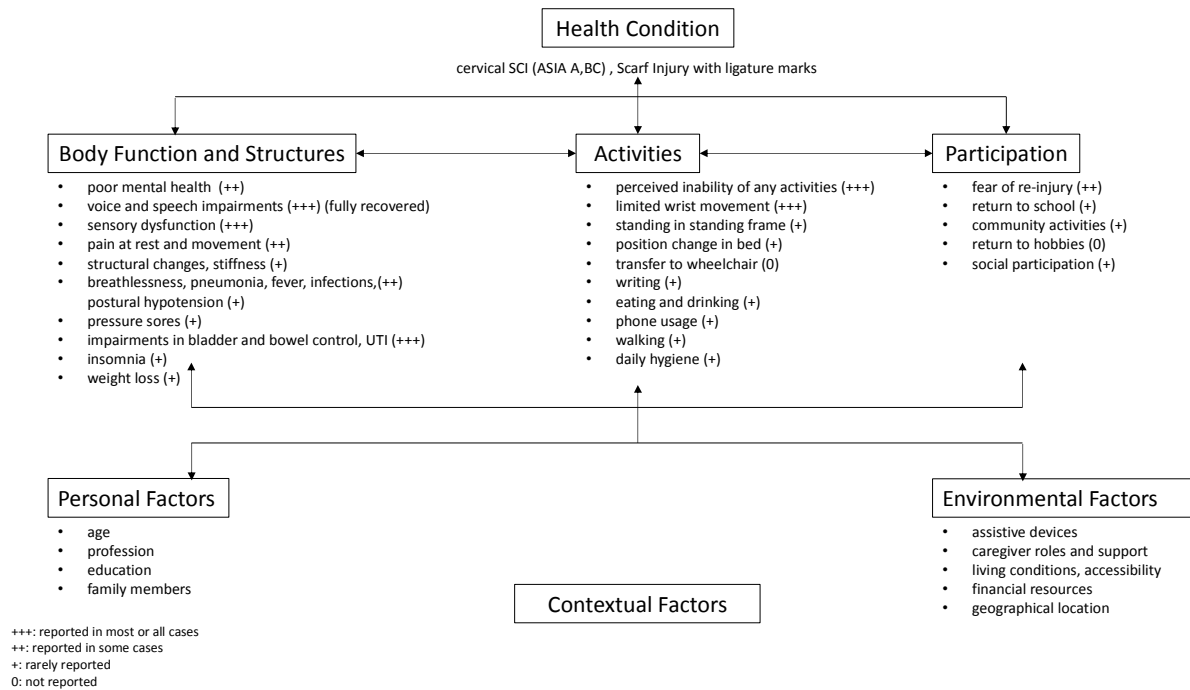


Figure 4: Overview of Scarf Injury ICF Model

Health Condition

All interviewed participants suffered a Spinal Cord Injury at the cervical level.

Based on the participants' medical records, the majority suffered a complete lesion and were diagnosed with ASIA A. One of the participants sustained a level C incomplete, another one a level D incomplete lesion.

Based on the hospital records of the patients, the skeletal level of injury ranged from C3 to C5, including two cases without a skeletal fracture. The majority of cases was diagnosed with a neurological level of injury at the C4 to C6 level.

Most females presented at the rehabilitation center according to the medical records with ligature marks on the neck. 5 out of the 12 participants underwent surgery.

Body Functions and Structure

Based on the interviews the participants reported impairments in the following body functions and structures.

Voice and Speech

All participants regained their ability to speak and did not complain of permanent damage of the vocal cord, despite the strangulation and sometimes impairments in their speech during the acute phase of the recovery. Having a voice and being able to speak functionally was often mentioned as the only working body function by the participants.

INT: How much have you improved ever since, after the hospital and after CRP. Has there been any improvement in the last 4 years?

A8: In comparison of improvement from hospital to present is I am speaking now, (smiles) properly like healthy people.

Sensory Functions and Pain

There was a large variety in reported pain among the interviewees, from no pain at all, to constant overall pain. Pain was reported in both, the complete and incomplete SCI lesions. Localized burning pain was reported only in upper extremities. The range of sensation also greatly varied, some reporting the ability to identify touch throughout their entire body, to very localized areas in the upper extremity. Tingling sensation combined with pain was reported by one case.

A11: When body becomes too hard, stiff, when sufferings increase like tingling sensation, burning sensation, that time I feel worse.

Neuromusculoskeletal and Movement Related Functions

The two participants, that were diagnosed with incomplete cervical SCI, regained walking ability and did not report any limitations in movements, other than some pain in certain movements in neck and/or shoulder. In the case of the remaining women with complete lesions, some spasticity was reported. One female reported stiffness in her dexterity, another one reported structural changes in her hips, restricting her ability to sit. When asking the participants about their level of movement, the majority of cases instantly reported the complete inability to move any body parts at all.

However, as the interviews progressed and different questions regarding daily life were asked, the ability to execute selected hand movements were often reported. Yet, those

possible movements were not always translated into the respected possible activity level, such as using available elbow flexion to bring food to one's mouth. In a few cases, through additional questions or the input of the caregivers, we were able to learn that the patient participants were in fact able to perform several daily activities, such as drinking water with little to no assistance.

Interestingly, upon observations during the interviews by the researcher, additional movements in the upper extremity and limited trunk movements to weight shift in the wheelchair were noted, yet often not reported by the participants.

Actions, that were initially reported as impossible by the participants, were observed being performed by participants.

Functions of the Circulatory, Respiratory and Immunological System

Participants reported breathlessness, recurring colds and pneumonia, especially during the winter months, but also during summer when sweating increased and the participants stayed in their wet clothes. Some of the females reported hospitalizations, or the need for continuous medical home visits to provide oxygen. One female was on life support reportedly during the acute phase following injury. We were unable to receive additional information on what type of life support was necessary, during that phase, however throughout the interview, the caregiver kept referring to oxygen support as life support. Therefore, we assume, that oxygen dependency was implied by the reported

life support during the acute phase. In one case difficulties in regulating blood pressure during position changes was also mentioned. In that particular case, the postural hypotension was her explanation for the inability to sit upright and use a wheelchair; this female has been in supine position in the same bed ever since the injury, and does not have a wheelchair.

The occurrence of fever seemed often to be connected with infections, but was also reported independently with unknown causes, as well as insomnia and weight loss.

INT: You said sometimes when you get sick, you miss school. Do you get sick often?

A5: Yes, sometimes. I have severe breathing difficulty. I remain absent from school due to these breathlessness. That time I need to be hospitalized.

Functions of the Skin and Related Structures

Pressure sores were generally prevented, with only three cases reporting a history of pressure sores, one of which is recurring. The other two instances occurred while being in acute medical care and not in their home setting. The caregivers demonstrated a high level of awareness and knowledge about the risks of pressure sores and how to prevent those.

B8 (Mother of 22 year old): (...) If I wouldn't support her then within 2 months...If she stays in same position for 4 to 5 hours then she will develop blisters. (...) I have seen pressure ulcer in this type of patients in CRP too. I have seen that on my own eyes. So pressure ulcer also happens in some people while staying there. That's due to little bit negligence sometimes. I never neglected about her. I use alarm on mobile at night. If I get late to wake up at night, I myself start feeling restless that what's the matter, it's been late.

Genitourinary and Reproductive Functions

One of the married patient participants emphasized, that she does not experience any complaints in reproductive functions, and in fact, would like to continue to have sexual intercourse with her husband. Additionally, some of the participants reported a regular menstruation cycle.

However, urinary tract infections, and the ability to control or sense the need for bowel and bladder movements were mentioned repeatedly, possibly resulting in unexpected incontinence, which was identified as a limiting factor in social participation. The use of medications to initiate bowel movements was mentioned. One of the participant's caregivers talked about frequent diarrhea.

A10: Actually I have urinary infection frequently. Also infection is going on now.

INT: How often does that happen to you?

A10: Actually all time. Sometimes urination happens automatically. Actually it doesn't remain okay.

(*Participant claims, that she regularly has urinary incontinency)

INT: So is it difficult for you to manage the catheter?

A10: Yes, the problem is sometimes urination doesn't happen in the same way. If spasticity increase that time urination doesn't happen with catheter. (When spasticity in the legs increases, participant is unable to use the catheter for urination)

B10: Catherization can't be done while spasticity increases. That time urination doesn't happen, but again later on urination happens automatically and the bed becomes wet.

(*Mother clarifies, that during the times, the spasticity increases and no catherization is possible, the patient urinates spontaneously and unaware later on, wetting the bed.)

Activity and Participation

The WHO defines Activity as the “execution of a task or action by an individual”, whereas participation refers to the “involvement in a life situation”. (WHO, 2014)

A wide range of level of activity and participation as well as limitations in those domains was reported. In some cases, the level of activity seemed to be in line with the level of participation, however in many cases, the activity level did not translate into the participation. In the majority of cases, the first reaction of the participants was to decline the ability to do anything, when asked directly about their level of function. We found a stark contrast in many cases between what the participants would first report in terms of level of function, and what has emerged throughout the interview and caregiver input.

One participant, who was able to write with a splint, that broke and has not been replaced, self-reported the inability to do anything and not having any hobbies. Her only activity was to sit in the house, however throughout the interview we learned, that she was able to write and paint with her mouth, as well as sitting in a wheelchair for 3-4 hours at a time, drinking water from a bottle, eating pieces of fruit independently and was taken out in her wheelchair regularly by other children in the village. However, often the caregivers would share the patient’s perception to not be able to execute tasks and participate in any activities independently.

INT: Just tell us, you wake up in the morning, and then what do you do?

A10: Then I sit up, I sit up on wheelchair and stay on it, I watch television.

*Then after getting up in front of TV, I go to room and lie down for some time, then I take bath, come to room and again lie down.; INT: So what is keeping you from doing any work?
A10: nothing is causing any obstacle. Actually I can't do anything alone. Also I can't do own movement. When others will help then I would be able to do now. otherwise I can't do anything alone.*

Her mother about the level of function and activity of her daughter:

B10 (mother talking about daughter): By her.....She isn't worth of doing anything. What will I tell about her? She even can't move. If she can do at least something without support then she will be able to do something. Otherwise nothing she will be able to do. The truth is she won't be able to do anything in future if can't do without support."

In general, each participant mentioned the ability to lift and move their hands and wrists to some extent. The ability to eat and drink independently depended on the food that was provided and whether utensils are available. The ability to write did not necessarily mean that the females would indeed write. One of the participants reported a fairly high level of function based on her level of injury, indicating the ability to maneuver her wheelchair to a small extent, write with difficulty without having a splint, eat by spoon and operate her phone, however she was not using her function in daily life, as she did not perceive any need to maintain this level of activity.

*"INT: Do you write often? Do you try to write every day?
A9: Now there is no necessity of writing so.....
INT: And how about reading? How often do you still read?
A9: No, I don't do anything more now."*

The amount of time spent in a wheelchair also varied greatly. The majority of participants reported to be unable to perform daily hygiene tasks independently, however some reported to be able to brush their teeth, assisting in dressing and bathing. In general, the first reaction when asking what they were able to do themselves, was to decline the ability to do anything. One participant reported to be able to stand in a standing frame, a rehabilitation device that allows paralyzed individuals to stand fully supported.

In terms of participation, reluctance to participate in social interactions was mentioned in the majority of cases, even in the ambulatory participants. They reported a high level of caution when leaving the house and performing certain types of physical activity. The fear of re-injuring themselves was identified as a barrier to return to their previous activities and social life. Another barrier to participation were psychosocial factors, such as shame, poor mental wellbeing and the sense of being a burden on the family. Shame was reported specifically in relation to lack of bladder control. Psychosocial factors as well as the social support system will be analyzed in greater detail in part 3 of this paper. We have found a low level of self-efficacy in the domains of activity and participation. Even with the level of injury the participants suffered, the described and observed level of body function would allow for greater independence in certain areas. It appears that the restrictions were more heavily influenced by contextual factors, rather than body structure and functions. The restrictions that the participants reported

in social life activities (eg. school, interacting with friends), as well as daily life activities (eg. eating, writing, personal hygiene) could all be averted by adapting to the situation and altering the environment. What this means is, that the body structure and functions, such as lack of motor control of the lower limb or challenges in bladder control does not mean, that the participant could not return to school. Rather, those limitations in activity and participation was influenced by contextual factors, such as the participant's living environment, access to education and the role of the caregiver.

Contextual Factors:

Personal Factors

Table 3 provides an overview of the participant's personal factors and demographics.

8 out of the 12 interviewed participants were below 20 years of age at the time of the injury and all of them attended school. After the injury, only 3 of them returned to school. However, all three regularly missed school. The two participants who were wheelchair bound missed school due to secondary complaints such as infections and breathlessness, or the need for additional rehabilitation. In order to access rehabilitation services, the families travelled to a different city and stayed for months at a time. The one student, who regained walking ability would miss school a lot less frequent than the others, however when it was raining and the roads were too slippery, she reported to stay at home. The reason for that was the fear of re-injuring herself, if she would fall.

One of the students reported that she will have to retake a grade, after missing too much school due to ongoing rehabilitation away from home.

Out of 12 interviewed participants, 4 were married before the injury. One of them was left by the husband after the injury, the other was widowed before her injury, raising her two children with support by her family.

In another case, the husband, who is still very involved in the care for his wife and children married a second wife after the injury. The husband of the 4th wife and mother lives abroad to financially support the family. Only one of the participants was formally employed before the Scarf Injury took place. She will be able to return to her occupation. She is the only interviewee who will be able to financially support herself and her family in the foreseeable future. The remaining participants were housewives or students before their injury and generated no income.

Additional personal factors, influencing the functioning of the participants were internal emotional responses to their perceived level of function and capabilities.

The fear of injuring oneself by too much movement or certain activities was reported as a limiting factor, in both, the ambulatory and non-ambulatory women. Another great personal factor, was the mental wellbeing of the participants and the reported emotions associated with living with this type of injury. The feeling of guilt and being a burden on the family and community seemed to be a limiting factor to reach the clinically possible level of activity. Some of the participants made the impression to rather not ask for

additional support or the desire to leave the house, since this would mean an additional burden on the caregivers.

Environmental Factors

Living Conditions, Accessibility

The longest time since discharge was 4 years. Some of the participants returned to the rehabilitation center for further outpatient treatment.

The majority of participants lived in semi-urban or rural areas, where in most cases also the injury had taken place. After the injury, in two cases the participants moved back in with their parents, or closer to family to get additional support. Only one participant was unable to return home yet, even 4 months after discharge from the rehabilitation center, due to bad road conditions and inaccessibility of her house with a wheelchair during the monsoon season. She instead stayed with her family close to the rehabilitation centre in a guest house, creating another big financial burden on the family. Poor road conditions as well as distance were mentioned by several interviewees as limiting factors for participation. In the case of former students, one reason for not returning to school was the inaccessibility of the school building as well as poor road conditions. One of the students was able to go to school independently by Easy Bike.

Some houses were equipped with a ramp. In some cases, the families adjusted the home environment by replacing the bed, re-arranging the layout of the rooms and making the

bathroom wheelchair accessible. However that was not possible in all places, often due to lack of space or financial constraints. One participant reported to be bathed out on the street, since the family's washroom was not accessible with the wheelchair.

"INT: Why are you worried?"

*A1: Mam, I don't face any problem here. The condition of our house is very bad. The house is made of mud and small. My getting in and out of house will be difficult, my mother won't be able to do it alone. The floor level of the house is very high. If I want to enter in the house I have to keep the wheelchair outside of the house. I am safe here (*Guest house close to CRP) because wheelchair is closely attached (*wheelchair fits into the room and is kept next to her bed) with bed before wheelchair transfer."*

Assistive Devices

In the cases of the incomplete SCI lesions, no assistive devices were needed to perform daily life activities. The only assistive devices used by the participants with a complete SCI lesion were a wheelchair and a splint for writing. In one case, the participant did not have a wheelchair, due to her perception of being unable to sit up since her injury 3 years prior. Three participants used a splint, however in one case it broke a year prior and has not been replaced since.

One participant reported she cannot keep the wheelchair in her house, due to lack of space and inability to sit in it due to hip complaints. This participant required transport by ambulance to medical appointments.

Caregivers

Most of the time the participant's caregiver was the mother and extended female family members (eg. Sister-in-law). In most cases, additional family members such as aunts and uncles or grandparents lived in proximity to the participant's direct family. In one of the cases, the family could afford to hire aides that assisted in the caretaking and household activities. The role of the caregivers in a psychosocial context will be discussed in greater detail in the third part of this thesis.

Individual: The Scarf Injury Survivor and her Direct Environment, Biopsychosocial

Model



Figure 5: Biopsychosocial Model

Concerns over own Physical Health

Patients and their caregivers mentioned health concerns, and how those are limiting their participation. Commonly reported concerns of the patient's health were breathlessness, infections, difficulties in bowel and bladder management, as well as pressure sore prevention.

Daily Life and Environment

Activities, Freedom and Security

We found a variety in levels of independence in the patients, which often interfered with the family's participation. Some participants mentioned the ability to speak as an (sometimes the only one) activity they can do independently. The lack of independence was often linked to being a burden and having to live on everyone's 'mercy', as described by one participant, directly influenced the mental wellbeing of the patients.

Upon asking about their daily life and how a regular day would look like for the families, the patients often reported passiveness and the inability to do anything independently.

INT: Can you name 3 things that are really challenging or difficult for you to do?

A12: Actually I can't do anything. I can't do any of my own work.

I can do nothing. I can't do any of my own work.

I depends on other people.

Environment

The living environment was in some cases adjusted as well as resources and the housing situation allowed, by building ramps and rearranging the room set up, if needed. In one case, the patient moved to a different city to be closer to family and a support network with her children and husband. In the cases of the younger participants returning to school, those were equipped with ramps as well. In several cases there was no space for the wheelchair in the room the females lived in, increasing a sense of insecurity. The wheelchair was instead kept at a family member's house or outside of their bedroom. Therefore, the females knew they would not be able to leave their room quickly, if necessary.

Some of the rooms we visited were not accessible by wheelchair due to steps or lack of space. In one case, the bathroom was not big enough for the wheelchair, so that the female was bathed on the open street in front of the house.

B9 (Grandmother, talking about the bathroom, that is inaccessible by wheelchair, and therefore they have to bath her granddaughter outside): Even we can't make the place to make her bath by taking her outside.

Transportation was often mentioned as a limiting factor to engage in any activities, such as attending school. Assistive devices such as splints for writing, when broken were not replaced, or not considered as a possible aid in the first place, limiting the level of independence and activities of the patients.

Emotions and Spirituality

Personal Relationships

Personal relationships with their family members and friends provided a sense of security and safety network in both, mobile and wheelchair bound patients. Some friendships did not continue after the injury, mainly in the cases, where the survivors did not return to school. However in other cases, friendships after the injury were reported as loving and caring.

The family relationships especially with the mother was mentioned as the most important relationship the survivors needed. The relationships between mother and daughter were in most cases very strong and their bonds positively influenced the mental wellbeing of each other. This bond was often perceived to be the strongest and most innate one to have. While a mother is naturally accepting and loving towards their daughter, one participant voiced that others might feel strong negative feelings and against a Scarf Injury patient and stigmatize them.

B11 (mother of 34 yr old daughter): The way mother looks after her, will any other person do like that? Never. Mom doesn't have any feelings of hatred.

The bond and interactions between siblings, especially in teenage participants seemed to not have been influenced by the injury.

In all three cases, in which the patient participants had children of their own, the children were both, a support and motivator to regain function as well as a source for emotional distress, when the mothers were unable to care for their own children.

INT: What about taking care of your children? How do you think that will look like?

A2: About looking after, I can only watch them, can't do anything by hand. If my older daughter comes close to me, sit on my lap then I can hug her. Only this.

INT: Does she do that often? Sitting on your lap and hugging you?

A2: Yes. She loves to get on lap and strongly wish to get on my lap. That's why whenever I gets on wheelchair, I take her on my lap once.

(pause for translation)

Sometimes my daughter asks me that if you recovers whom do you take on your lap first. Is it new baby or me?

INT: And what do you say?

A2: I reply her that no I will take you first as you are my older daughter.

(pause for translation)

Then she says you are very good and kiss me. And tells do take me first on your lap.

B12 (female family member): she always tells that I am, however how long Allah keeps me alive in this state, so that I can see that my sons become something big like good human being. This is her only wish.

During the interviews, more female family members were involved and voiced their concerns about their family member with a disability, but the male family members who were present, were also supportive and concerned about their wife's, sister's, sister-in-law's or nieces wellbeing.

In one of the cases, the mother raised her two children independently, after her husband left many years ago. She expressed to be initially overwhelmed with the situation, having to take care of a disabled child by herself. The relationship between her and her

two children was very close and supportive. Both, the mother and daughter strongly believed, that one day, her daughter will be able to take care of her mother again.

B5 (single mother of 13 year old daughter): She observed from her childhood that how I did hardship. One thing stuck inside her when she was kid that she will do study, do job and then she will make me... in childhood she couldn't say that but used to say that I will make you eat by leg means she will feed me by keeping my one foot over another. She couldn't say that. When she had accident that time..

(pause for translation)

I forgot what I told before.

(pause for translation)

After accident she used to say like this that don't take me away from my mother by keeping her eyes closed. Oh my mother, I couldn't fulfill your hope. I won't be able to be doctor anymore, when she couldn't move her legs that time she said like this. Allah, don't take me away, who will look after my mother? I will look after her.

In one case the husband left the Scarf Injury victim at the day of the injury, as soon as he heard about it, and neither him or his family have been in touch with the victim ever since. Another participant reported that even though her and her husband still have a lot of love for each other and continue to raise their two children together, the husband remarried.

A12: Actually my husband didn't want that because he was with me for these 4 years. He was with me for 4 years but in between the situation became like that I can't do anything, and he is very big, he has many responsibilities as district election officer, he works in a very high rank, he can't come to me on time. So he... he was very sick in between. The loneliness and his job is transferable, he went far away, who will take care of him like who will cook food for him, so thinking about those other sides, sometimes I understand these things but sometimes I don't understand.

INT: So you know that he did not marry someone else because he doesn't love you anymore. It's more because he was looking for that support when he is not here and in the everyday life?

A12: No, no. this is not the thing.

(pause for translation)

A12: Yes, one girl and one boy have many differences. One girl can stay like this. It's nearly impossible for a boy to stay like this.

As mentioned earlier, the husband of one participant lives abroad for many years now, in order to financially support the family. In one case, the survivor reported that after the injury her uncles stopped engaging with her. Another mother of a Scarf Injury survivor reported, that she received more moral and continuous financial support from her community rather than her direct family members.

B6 (mother of 14 yr old daughter): I have brother. My brother is helping me to some extent, also village people are helping.

INT: How do they help?

B6: After this accident, we spent all our accumulated money. We have to maintain our livelihood, we have to do treatment but we don't have any money. We are continuing treatment by combined financial support of all people.

...

INT: And how about family members? How that relationship changed?

B6: Actually those who are my own relatives, they aren't helping me. Rather other peoples are helping.

INT: Why do you think your relatives are not helping?

B6: Actually they don't have money, how they will give us?

INT: Do they support you through something else? Maybe with helping with X, or is there any other support that they offer? Any help?

B6: No, no. They used to come and help at very beginning. Actually all have work. Who will come when?

In general, the form of personal relationships, either being supportive, isolating, motivating or diminishing could be directly linked to the participant's and caregiver's wellbeing.

Emotional Wellbeing

The emotional wellbeing of both, the patients and caregivers were multi layered and sometimes contradicting responses were given. A lot of emotions were directly linked to physical health and relationships. In both groups we heard a lot of emotional responses, crying and from caregivers even the inability to continue the interview or share specific experiences of the injury, as it was still too traumatizing to share, sometimes years after the injury. The life of the survivors was describes as 'average' or not being existent anymore. The feeling of being a burden and having to live by the support and grace of other people, was described as being 'painful'. That financial, logistical and emotional burden on the family was linked to a feeling of guilt and shame. The family dynamics shifted due to the injury. In some cases, the females described, how life 'should look like' for them, being supposed to be in school, or being supposed to take care of their mothers and children instead of having switched roles.

A9: today if I was in good health, then I wouldn't need to stay in a room like in this way. My all friends go to school, sometimes they meet me, after 1 to 2 days later they meet me by coming here. I too was supposed to be like them.

Many participants reported a sense of continuous hope of full recovery one day, while at the same time being helpless and mentioning they are unable to do anything themselves. The caregivers did not share a lot of their own personal feelings, as they perceived those to be less important than those of their daughter. If they did share insight on their emotions, some would mention feeling overwhelmed and feeling isolated.

Coping

There was a wide range of acceptance of the situation after the injury. Generally, the coping and level of acceptance did not differ between the patients and their respective caregivers. If one of them demonstrated a certain coping style, the family seemed to follow that.

A8: Also everyone have to die someday if comes to earth, everybody should remember that. And maintaining livelihood is painful, also people have to struggle if want to live. Hence, life is not smooth.

(pause for translation)

You have to accept the reality if you want to live.

1) Active Acceptance: 5 of the 12 participants seemed to have adapted effective coping stiles, however it is to be noted, that two of those participants regained walking ability. I all the 3 remaining cases, who were wheelchair bound, were those with an outlook for the future and a purpose, such as education, returning to an occupation. In fact, the active acceptance group included all students who resumed their education, as well as

the only participant of our sample who was formally employed and was given the opportunity to return to her profession afterwards. Her employer made necessary arrangements to create a disability adjusted work place for her.

Those who demonstrated active acceptance, were participants and caregivers who were able to set realistic goals for improvement and were willing to adapt their lives to the given circumstances, in order to become as independent as possible. Some caregivers would be willing to spend more time and money on rehabilitation and medical care to reach their family member's full potential.

However, the active acceptance mindset, that we have observed, did not mean, that those survivors did not face any psychological challenges at all, however they were able to better cope and work with negative emotions and challenges.

Whereas the socioeconomic status of the families did not seem to correlate directly to any of the above mentioned coping styles, it was apparent, that in the active acceptance group, all three had a vision, that the patient participants will one day be able to pursue a career and support themselves financially.

2) Passive Acceptance: This group of 4 participants was hoping for full recovery and was passively waiting for a miracle and higher forces to enact a full recovery for the Scarf Injury patient. They were often unable to actively attempt to improve their skills nor live up to their functional potential, believing one day they will resume their old lives without having to invest in that change. 2 of the 4 participants in this group were above

30 and mothers of young children. One of the mothers did mention occasional suicidal thoughts in times she feels very sick and is in severe pain, however the presence of her daughter motivates her to stay alive.

3) No Coping: In 3 cases, we could not identify any coping strategies, and the participants would not see any meaning in life anymore, unable to accept their situation. All three of those reported their wishes to end their lives or rather would have wanted to not survive the injury in the first place. In all three cases, the participants were students (Highschool or college) before the accident and were unable to return to school. In all three cases, the caregivers openly voiced their sense of hopelessness and grief and in front of the patient participants.

INT: But who said that it would be better if you die?

A8: I said that.... That today the condition I am in..... the sufferer who is suffering It would be better to die on that day rather than suffering like this.

Suicidality

There were no suicidal thoughts reported in those cases that had some future plans and goals, that they were working towards to.

Four out of the 12 participants report suicidal thoughts (33%). Some were linked to specific situations in which they felt particularly ill and helpless due to poor physical health episodes.

INT: And how often does that happen, that you wake up in the morning and you do not feel good?

A11: When body becomes too hard, stiff, when sufferings increase like tingling sensation, burning sensation, that time I feel worse. That time I don't feel to die. That time it comes to my mind that let my daughter grow older a few more years then Allah let me die. Again when I feel worse, watch my mom's hardship, that time I feel to die.

The family and loving support of the family members was usually the main reason mentioned by the participants to not commit suicide.

However, that love for the family was also mentioned as the reason to take their own lives, in order to take away the burden on the family, which was considered to destroy the family. In one case, a young female reported, that her family members in moments of their own desperation and helplessness mentioned that the death of the Scarf Injury patient would be better for everyone in the family.

It was mentioned by two participants, that Allah should take their life, which reflects that same passivity and lack of control over their own lives as mentioned above in the coping mechanism and daily activities. The cases that repeatedly mentioned their suicidal plans were willing to commit that suicide even though it was against their religious belief, in order to relieve the burden on the family.

INT: So what are they telling that you cannot tolerate?

A9: (cries) Actually parents will do everything for how long I am alive but still don't people feel restless that the same work repeatedly, calling mother to do urination, everyday it doesn't feel good, also for me everybody will suffer, things not like that.

INT: But don't you think they will really miss you when you are gone?

A9: But no one will suffer for me.

INT: Have you ever talked to your family about how you feel about that?

A9: (silence)

INT: How do you think they would react if they know what you're thinking?

A9: but they will stay fine at least. They will be more fine than now.

Religion and Spirituality

The big majority of the interviewed families identified themselves as Muslims. The other two families followed the Hindu religion.

Their beliefs generally seemed to increase a passive attitude towards the situation. A lot of challenges and questions about future plans were answered with the faith in Allah to solve those challenges. The responsibility and ownership over the course of their future lives were handed to Allah in many instances, creating a barrier for improvement in function.

INT: What do you think will happen in the future? Do you have any ideas?

A12: (smiles) future is written by Almighty God. What will happen in future or not. It won't be fine to say this.

(pause for translation)

A12: No, it won't right to say that Almighty God writes this.

Their faith was believed to be the reason that the females were still alive, and whether they have recovered or not recovered yet.

INT: describe exactly what you mean by becoming well.

A10: No, I do have faith on Allah. If he recovers me someday, then..

INT: Do you think she saved your life?

A2: (translator does not know how to translate, A2 rephrases her response). I feel this slightly. Allah saved my life ultimately but she has great contribution in that.

To some extent, their religious belief seemed to be a support in coping with the situation and the ability to pray for betterment seemed to give the families some control over the situation, having an action that they all could do. Their strong beliefs were not questioned after the injury, except for one case, who reported her faith has decreased slightly after the injury.

INT: X, how important is religion to you?

A7: Religion is usually important. It is important for some extent. But people from every religion is same.

INT: And how did your religion help you after the accident?

A7: It didn't help in any way.

INT: Did anything change in your belief after the accident?

A7: Sometimes I feel like there is no God, nothing like this.

B7 (mother): She lies on bed all time, can't move limbs. If God would recover her, then she would be devoted to religion.

C7(father's aunt): It's not possible to do pray of 51 gods. Oh my God. That's why. Apart from pray..... in this world we can't visit traditional healer. She treated in Vellore. Even went to Delhi.

Another teenager however, decided to read the Quran during her rehabilitation phase, to support her recovery. She has almost fully recovered. However she did not mention that act of reading the Quran or her belief to have positively influenced her recovery. A few women thought of their injury as a punishment for sins they had committed in the past.

INT: Has anyone of the doctors or therapists explained what a Spinal cord injury is?

A1: Yes, they do. Still I can't believe them. Madam, I am losing my patience. I am in lots of pain. I feel like committing suicide. I strongly don't feel to live like this. What sin I have committed? Why God is punishing me like this? Why God is giving me miseries from such young age?

INT: How did you experience that time, going from hospital to hospital? How much did you know what was happening to you?

A1: I felt like my life has been ruined. I don't know why I feel as I have committed great sin.

Part of their belief also influenced the earlier mentioned passive coping strategies that influenced the sense of ownership over their functional improvements and level of regained function.

INT: your daughter has already told us a lot about the accident and the injury and the journey until now, so we just have a few questions about the life now and how those changes were for you and how you experienced this.

B2: What my experience is? You are watching the whole situation. I am listening and understanding about this from doctors. Since the event I came to daughter and living with her. I pray to Allah for her recovery. Doctors are also saying that it will take long time and if Allah wants she will recover. The accident already occurred and her body became paralyzed. She won't be fine until Allah's will. Sirs told that she won't be normal like us but keep patience there will be some improvement. I am watching her improvements. She was completely bed ridden, couldn't move hand now she can move her hand upto mouth.

3.3 Challenges and Facilitators for Community Reintegration, Future Needs and Perspectives

After having described the clinical range of outcomes, level of functioning and activities as well as details of the injury and acute care, this part of the paper will now explore the life after the injury in the community. In order to portray the how the social network,

family dynamics and relationships all influence the individual and the success of community reintegration, we will use parts of the Bioecological Model by Bronfenbrenner (Patel, 2011).

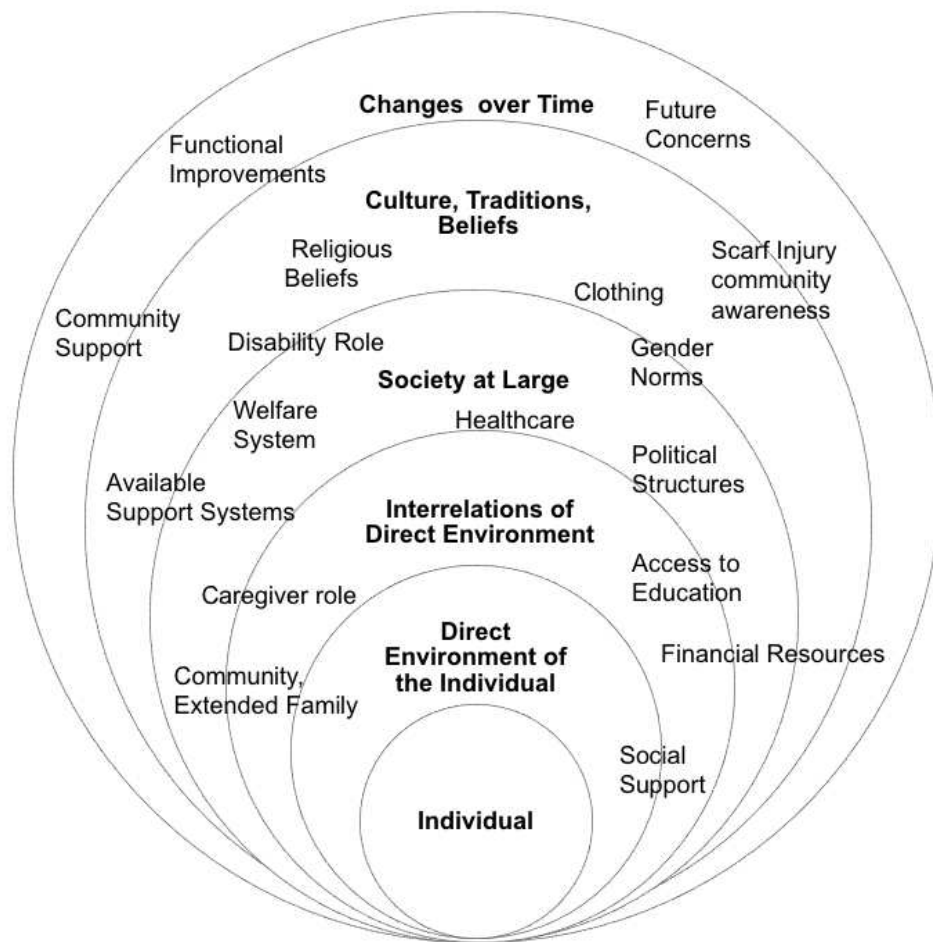


Figure 6: Bioecological Model

Linkages between Family and School, Religion and Family

Support System

Social Support

The social support system included direct and extended family members, neighbors, and in some cases the schools of the female survivors. The family support was however considered to be the most important support system for the survivors after discharge, not only to provide a safe environment and meeting their basic needs, but especially for their emotional support. However, in one case, the family did not serve as a mental support system, as they openly fought in front of her, discussed the struggles they were facing because of this injury and not following their promises towards her daughter, further deteriorating her emotional wellbeing. When the Scarf Injury survivors were mothers, their children provided a great deal of emotional support, and encouragement, by their unconditional love and affection towards their mothers. When the children were old enough, they would provide assistance for the mother in daily life activities. The mothers felt reassured that their children will be able to take care of them later on, if necessary. Extended family members, generally females were also an integral part of the support system, mainly for the caregivers. Male extended family members were not mentioned as a support system, other than for financial support. Those families that supported their family member, encouraging and supporting her independence, demonstrated an overall better psychological state of both, patients and caregivers.

The support system for caregivers was underreported, as the caregivers themselves would refuse to talk about their own needs, but rather mention their daughter's needs. The caregivers would often report that there is no one that is supporting them to take care of their child, which was not always supported by our observations during the interviews.

B8 (mother of 22 yr old daughter): I am not finding a single person even for a single day. I will go to visit doctor for my treatment for a single day, still I am not getting any person. How will I expect? Also my mother isn't alive, I don't have brother, I had mother-in-law, she had stroke. Actually we don't have that kind of person.

Generally, the patients and primary caregivers mentioned a decrease of social support from extended family and community members over time.

B8: When she was studying, there were friends. Now she isn't studying so there is no friend. People don't stand beside at bad time, but stay during good time.

(pause for translation)

A8: there is a proverb saying that people stays beside you during good time.

B8: Yes, no one stays beside during bad time. Now we are in danger, I don't have anyone.

For those, who were in school age at the time of the injury, school was a big support system, and the engagement of the schools seemed to highly increase the chances of resuming their education and continuing to have a social support system through their peers in school. Being able to return to school and having the support through the teachers was an important protective factor of friendships and psychological well-being.

Caregiver Role

In all families, the primary caregiver was a female. Other than the one case, who was able to hire external caretakers, the caregivers were in most families the mother of the survivor. However, also the sisters-in-laws were often highly involved in the caretaking of their family member. Generally, the mother however had full responsibility over her daughter's wellbeing and life. That big responsibility led in many cases to negligence of their own health, as well as the feeling of being overwhelmed. The burden on the family further increased by the caregivers not being able to continue their income generating activities. In the situations where the mother served as a primary caregiver, their own increasing age, decreasing level of fitness and lack of additional support was mentioned as limiting factors for participation of both, the patient participant and the caregiver.

The caregivers, in all reported cases the mothers, indicated own health concerns, and the inability to seek continuous care, due to lack of financial resources and the lack of social support in the caretaking of the daughter. In addition to that, some mothers reported, that their health is not as important as the daughter's wellbeing, sacrificing their physical wellbeing to continue the sole caregiver role for their child.

The mothers demonstrated an almost self-sacrificing behavior to carry the burden of caretaking, acknowledging that without them, their daughters would be unable to survive.

One mother who was living with her sons who took care of her due to her advanced age and medical condition was forced to move in with her daughter and become her caretaker.

INT: How much longer do you think you can keep taking care of your daughter the way you do now? Are you worried that one day you won't be able to do that anymore?

B11 (mother of 34 yr old daughter with child): The long Allah give me ability.

C11 (sister in law): The long she will be alive, she have to do these. Who will do these? If she dies, then Allah will look after.

B11: I think about that, cry, cook and eat. Then maintain livelihood with 5 more people.

A11: Allah is above. There is no one else than mother.

B11: If I become sick today, then the way she is lying now, she will be in same condition.

(pause for translation)

C11 (neighbor): there is no one to look after her by this way.

The role of caretakers was defined as providing physical but also emotional support. The need for having a loving and supportive caregiver was mentioned by several survivors as one of the responsibilities of the caretakers.

The perceived responsibilities of caregivers were twofold: Some mentioned their need to fully support their family member and do everything for them, whereas other caregivers who accepted that a full recovery is unlikely in the future pushed their family member into greater independence and active coping strategies, acknowledging that promoting independence was often more difficult than simply doing the tasks for their relative.

C3 (mother): When she sat on bed to eat rice, used metal tray and pillow over tray that time rice was used to fall apart, her hand couldn't reach mouth, that time I sat beside her and feed her. She used to eat a small amount of rice. If she couldn't eat that then how will she survive? During that

time Z. (counselor of CRP) sir came and I got irritated inside. He told that aunt, what are you doing? I replied that no, son; she couldn't manage eating rice and rice has been falling. He said, let the rice fall. Again bring rice on plate. She will drop and you will give her rice again. She will eat whatever amount she can put on her mouth. Don't feed her, I warn you. It is like killing her by feeding her. I said oh Allah.

.....

INT: And looking back at that, how helpful was that behavior for you during the rehabilitation? I am sure in the beginning you were annoyed.

A3: Sometimes I thought that she was doing that for my betterment, sometimes I used to laugh, sometimes felt bad.

Upon asking about their own level of wellbeing, they would often report a feeling of being overwhelmed and left alone in the caregiver role, but in the course of follow up questions, we would find out, that in most cases the primary caregiver had a functioning support system around them, that offered some possibilities for task sharing at least.

Community Relationships

Community integration happened mainly through relationships with students and teachers through their schools as well as the relationships with their neighbors. Those community relationships were considered to be protective and encouraging social integration, when the females returned to school and through support of neighbors and family members that allowed the patients to participate in community activities, such as playing with neighbors on nearby fields or joining religious celebrations.

INT: And how do you think your daughter is experiencing the relationships? Is that the same for her?

B10 (mother of 16 yr old daughter): Yes, similar. They loves her more than me.

INT: laughs) more than you?

B10: Yes. No one speaks any word in front of her that can hurt her mind.

INT: They are very protective of her.

B10: Yes

Five of participants did not regularly leave the house to interact with the community, one female has not left the bed since she suffered the injury several years ago and did not possess a wheelchair. Those who did not leave the bed of house, isolated themselves more and started refusing community interactions. For females that were housewives before and did not have a school or profession to return to, that could serve as an aid for community reintegration, they remained mainly isolated except for some neighbors visiting them sometimes. Even the two females, that recovered and were able to walk again, were restricted in their community relationships, due to their lack of confidence to interact in crowded places and fear of re-injuring themselves.

A connection to their schools was mentioned as the biggest factor for positive community relationships. It was reported that overall the community members lost interest to support the families over time, except in one case, where the village members continued to financially support the participants, when their own family would not anymore. It was mentioned, that the ignorance of community members and not knowing how to behave around a person in a wheelchair would limit the females'

willingness to participate in community activities, negatively affecting their mental wellbeing.

INT: And how is it for you when everyone asks you why you are in a wheelchair and how it happened?

A6: Yes, that time I feel bad.

INT: I only just met your family, but everyone seems very concerned and seems to have a lot of love for you, so I can imagine they would really miss you.

A9: But I am in pain also. When someone come to see me and say that how beautiful the girl is and she is living like this, that time I also feel bad.

Financial Resources

INT: But do you think you can with help? With training do you think you are able to learn certain things again?

A11: I can do but it seems like you require people with you. There is no one to look after. Everything in combined. Don't understand this?

(pause for translation)

We are not rich, we are poor and general people. Now the problem I do have, that's a problem of rich people. Those who have manpower, boundless money, keeps 2 or 1 people for household work, keep people for doing exercise, isn't it? Now we are very poor.

(pause for translation)

Money requires for everything. Don't you understand this? People can't do anything without money.

As mentioned earlier, the costs during the acute care was said to be as high as approximately 6000USD.

In addition to those costs, the ongoing medical treatments increased the burden on the families in the majority of interviewed cases. One family was able to afford two external

caretakers. Those, who are mobile and recovered from the injury, did not report any financial burden, however were also in better financial standing than the majority of the other families included in this study before their injury.

Associated ongoing costs were especially the management of secondary complaints such as infections, fever, urinary tract infections and breathlessness. Medications for bowel management and catheters were also constantly needed medical supplies. Transportation costs to medical facilities were also mentioned as another cost. One participant reported to be able to return to work as a community health care provider and generate an income during her rehabilitation phase, thereby financially supporting her family.

Additional burden on the families was the loss or decreased income by the caregivers. Many cases reported that their families had to sell some land and their animals to cover the medical costs. One mother, who took care of her daughter and young son was able to start her own business while caring for her daughter and provide a steady income for her family. She lived separately from her husband and is the only person in the family that could generate some income.

The support from family members mainly in the acute phase was mentioned. After the discharge to their homes, ongoing financial support of the community and schools was reported in some cases.

The financial situation limited the rehabilitation access as well as access to medical care for the caregivers, due to the inability to pay for transportation, housing and treatment costs. In one case the husband lives abroad to provide income for the family. One family estimated the monthly expenses to be around 15-16.000 BTK (180-190 USD).

Education

As indicated in Table 3, only three of the eight participants who were students before the injury returned to school after returning to their homes. However, most of the remaining five wished to return to school and continue their education. The return to school seemed to be a protective factor for mental health and the reported wish to regain independence. Those who returned to school seemed to have clearer ideas about the future and realistic visions of functional independence, reporting education as the key to be (financially) independent later on. Limiting factors on returning to school were transportation, assistance in school such as writing proxies, financial resources, the perceived uselessness of school when unable to write, as well as the active engagement of the parents.

INT: And have you been, do you know if your family has been talking to your school after the accident?

A9: Yes, they talked and they agreed too but mam, what they says by mouth, they can't express that by their activities. They just speak big things by mouth only.

INT: The school says big things by mouth only?

A9: No, my father and mother.

The active involvement of the school and communication of the teachers with the families was a big facilitator in motivating the parents to send their children back to school and overcome the above mentioned challenges.

The school was identified as a tool for community reintegration as it allowed continuous interactions with their friends and peers. In the cases, where the school-aged patient participants did not return to school, previous friendships with fellow peers decreased. Being unable to return to school increased their sense of social isolation and reported loneliness, leading to the rejection of friends who continued to visit them in their home.

INT: So when was the last time you saw your friends?

A9: 2 friends came at yesterday night.

INT: And was that when you told them they should not come back?

A9: yes

INT: And what did they say?

A9: They told okay, we won't come. But still they come.

....

INT: So what do you think needs to happen that you believe them it is not pity. (clarification for translator). What can make you believe that they just want to spend time with you?

A9: I know that they treat me like earlier. But I don't feel like this. I feel like this that they are showing mercy on me.

INT: But actually you do know, that it is not pity but they just want to spend time with her friend?

A9: yes

Society at Large: Political and Ecological Systems, Culture, Rules

The cultural and religious context of Bangladesh as well as the role of females in the society plays a big part in the challenges and possibilities for a successful community

reintegration and maintaining a high quality of life of the survivors. This type of Scarf Injury is very culture specific to the Asian context, in which females are culturally bound to wear a scarf as part of their traditional clothing. Therefore, this injury almost exclusively affects females in this specific setting.

As presented in this study, the healthcare system in Bangladesh and lack of insurance schemes, often created catastrophic health expenditures for the survivors and their families, due to the high amounts of out of pocket payments. One participant reported the death of a community member who suffered a Spinal Cord Injury but had no financial resources to access care.

The role of culture, gender and religion will be explored further in a separate analysis, taking the expert opinions of medical and rehabilitation professionals into account. The overall healthcare system, that demonstrated great deficits in acute care management, as well as the detrimental health care expenditures the families were facing further increased the difficulties of the families to support their daughter, sister or niece appropriately. We have reason to believe that the lack of knowledge about Spinal Cord Injuries, Scarf Injuries as well as wheelchair bound persons with disabilities not only negatively influence the injury outcomes due to poor access to care, but also negatively impacted the overall wellbeing of the patients and their families.

INT: What do you think, the people in your village should know about your condition, so that they don't have to ask?

A6: They should be informed that hands, legs become paralysed after scarf injury.

Changes over Time

The time since discharge from the rehabilitation center ranged from 4 months to 4 years in the participants. The one female, who was discharged 4 months ago, was unable to return to her home yet due to the rainy season and inaccessible roads with a wheelchair. Overall, time since discharge did not seem to have a big impact on the acceptance of the situation and future goals. Some participants, also years after discharge mentioned the desire to return to school or the hope of full recovery. The degree of improvement after discharge also varied from no improvement at all to being able to independently conduct several activities, such as eating certain foods, writing or aspects of daily hygiene. Future concerns were raised mainly by the participants, both the patients and caregivers in terms of caregiving abilities in the long term future. The fear when the parents will be physically unable to care for their children anymore, was mentioned several times and a big contributor to the emotional wellbeing of the family members. Over time, changes in caregiver support by neighbors and extended family members were reported in some cases with decreasing interest or abilities to help.

Future Needs and Perspectives

Future, Goals, Perspectives, Needs

Going forward and asking about future needs, plans, goals and dreams the responses were very wide spread.

The majority of participants and their families refused to abandon the possibility of a full recovery one day, regardless of how long and severe the sustained injury was. Many times, the families would leave the possible recovery in the hands of their faith, which also prohibited them to make future plans themselves, as their path would be guided by their God and not themselves.

Those who had plans and wishes for their future, were sometimes unable to identify how to achieve those goals, such as having some kind of work to do, that would help them pass the time. They seemed incapable of finding realistic goals that could help to achieve their long term goal. One participant wanted to return to school, but her and her mother said she did not know how to do that, if she wasn't able to write by herself. However, they also did not take the initiative and ask for support to solve those problems, such as by having a proxy in school or trying out a splint. Some females who accepted that a full recovery would be fairly unlikely, were able to identify realistic goals in terms of functional recovery that could increase their independence.

INT: And what kind of help do you need to get to that point? What kind of support do you need to achieve this goal?

A5: The thing I need most is therapy. If I take therapy, then I will be able to do so. And my own try.

The possibility of an occupation or some labor in the future was mentioned by four participants, one who was able to return to her previous employment, and three were currently in school. Only two participants discussed the possibility of being able to provide for themselves.

INT: And when you think about the future. How do you think your future will look like?

B5 (single mother of 13 yr old daughter): My future? (laughs) My future is my daughter will build me a house by doing job.

INT: What are the next steps to make sure your daughter can build you and her a house?

B5: (laughs) What my daughter tells me, you know? She tells like if someone does study well then they don't need to search for jobs. People will appoint me by my qualification."

Those who were housewives and mothers before the injury had difficulties identifying future goals. One female reported that she does not have a future and would wish to not live another five years.

INT: If you think about the future or the next 5 years, the next 10 years. Do you have any thoughts about this time? (no translation required)

A8: No, I don't hope to live for 5 years or ten years. I always thought that I sleep at night and may be I am no more in the morning. My everyday goes like this.

INT: So you are living day by day and not having thoughts about the future.

A8: Yes. For me, my future is dark.

INT: Do you think there is anything that you would like to do again?

A8: What will I do? (smiles) The word "do" is not applicable for me.

The wish for financial stability was mentioned as well, mainly by the caregivers. The caregivers usually did not mention any future plans of themselves when asked, but would respond in the interest of their child. The main goal mentioned by the younger participants was the strong desire for education and returning to school. One teenager reported, if she wasn't able to return to school, she would die.

INT: ok. (pause) So if you don't go back to school and study, how do you think your life will look like otherwise? What else are you going to do?

A9: I will die.

INT: Why do you think you will die, if you do not go to school?

A9: Everybody is suffering for me. If I don't be alive, then no one will have to suffer.

INT: So if you don't go to school, and you said you will die, does that mean, if you don't go to school you want to take your own life? Are you thinking about taking your own life if you don't go to school?

A9: yes.

Advice and Prevention Ideas

We ended the interviews with asking about the participants' future plans as well as advice for other Scarf Injury patients and their families. The responses were in line with the general emotional state the participants were in. Those participants who had had no encouragements or advice to give at all, seemed to not be able to successfully cope with the situation themselves (patients and caregivers).

Prevent Secondary Complaints

In addition to that, it was stressed to follow CRP's advice and prevent secondary complaints by cleanliness, personal hygiene, and being cautious in movements for those who were able to move independently.

Emotional Support

The need for emotional support was mentioned by both, those who experienced social isolation and feeling hopeless, as well as those who experienced a very loving and supportive network.

They advised future caregivers to especially provide emotional support and take care of the psychological wellbeing of their family members.

A11: (starts crying) Those who look after them like father, mother, may be guardian. Don't they speak many types of speech by getting hurt? We are already in pain. No one should misbehave with them. They should be treated with good behavior. They should be provided with that when anyone need anything. Because we can't do movement. We are living, moving on other's pity. We are living with other's mercy.

Promote Independence

Some caregivers perceived to show support by doing everything for their family members, however the advice given by those, who encouraged independence emphasized the importance of being supportive in the process of giving the patients the ability to try it themselves and encourage them while failing initially.

INT: (rephrased) How can a therapist or the family help to create that way of thinking in the patient?

A3: It is very important for the family to build him strong that yes you try, we are there for you at your behind. You will sit or lie idle by saying that you can't do it, we won't do that. You keep trying, if you fails after trial then we are here.

4. Discussion

To our best knowledge, this is the first study that presents the impact of Scarf Injuries, that are caused by the entanglement of the scarf in the engine of a vehicle. Additionally, we believe that this is the first study, that presents a Scarf Injury with such severe and distinct clinical injury pattern.

In this study, we have presented the great challenges the survivors and their families are facing to access and receive necessary care during the acute as well as long term stage.

We have also confirmed, that this injury, is easily preventable, by filling the gap between the two seats with a wooden board or additional cloth of the seat covers.

Additionally, once suffered this debilitating injury, it creates an immense burden of disease, requiring lifelong assistance and support.

The 'three delays framework', introduced by the Lancet's Commission Global Surgery 2030 report, describes challenges in the present situation by delays in seeking, reaching and receiving care. (Meara & Greenberg, 2015)

Though our study sample did seek care and reached care, though in unsafe modes of transportation, they did not receive the care they needed after having visited sometimes up to 6 health clinics. We have learned, that the survivors were confronted with a great lack of knowledge and awareness of Spinal Cord injuries by the public, who served as first responders, as well as medical professionals in acute care settings. Based on the

reports of the participants, we can assume, that the clinical outcomes could have been less severe in some cases, if they received appropriate care from the beginning.

Those findings support Sakran et al. (2012), that pre-hospital care is mostly impacted by the lack of effective emergency care and the availability of transportation. (Sakran, Greer, Werlin, & McCunn, 2012)

A study by Mock et al. compared trauma mortality patterns across three countries of different socioeconomic levels, and found, that pre-hospital deaths increased with decreasing national socioeconomics. (Mock, Jurkovich, nii-Amon-Kotei, Arreola-Risa, & Maier, 1998)

In addition to the lack of knowledge and abilities to manage SCI possibly causing adverse physical effects, we can also hypothesize that the bad experiences and lack of timely education about the nature of their injury, negatively impacted the ability to accept and adapt positive coping strategies early during the rehabilitation phase.

The females 'lost their voices' with this injury, their lives were disrupted and often times they did not know where and how to access the support and guidance to learn how to adapt to their new lives after discharge from the rehabilitation facility. The time spent in the rehabilitation center seemed to not have had a great impact on those challenges.

The psychosocial burden on the patients and their families was immense, and that sense of helplessness and hopelessness, often seemed to be emphasized by the lack of community support and social isolation. Each of the females had a specific role or

identity before the life changing event, whether it being a student, a housewife, a mother or working professional. After the injury, returning to those identities seemed to be one of the main facilitators for social reintegration and regaining a satisfactory, yet disability adjusted Quality of Life. Those students, who were unable to return to school, overall showed lower abilities to set realistic goals and were more likely to show signs of depression and social isolation.

Considering that the majority of Scarf Injury Survivors were students at the time of injury, it is crucial to pay attention to the effects this injury has on the education of the survivors. Sustaining a Scarf Injury results in long rehabilitation, life-long disability and the need for adjustments in all areas of daily life to adapt to the new circumstances. We have learned, that only 3 of the 8 students returned to school, after discharge from CRP. It is also important to note, that 1 of the students regained walking ability. Yet, all 3 students reported to miss school regularly, due to either ongoing rehabilitation needs, or secondary complications.

Educating females and keeping them in school however, has shown to have a great impact on decreasing poverty and positively influence a country's ability to fight poverty, which is in turn the biggest risk factor for young females to not obtain education. (Worldbank, 2017)

Additionally, poverty increases the risk for poor mental health, (WHO, 2005) which we found to be a big limiting factor in community reintegration. Therefore, we believe that

investing in the ability for the female survivors to school, will greatly influence the long-term outcomes of the survivors as well as their social network, by giving the females a chance to obtain financial independence for themselves through education. Since those females will not be able to perform any manual labor, the only way to support their families will be through their intellectual abilities.

Another important finding of this study is the gender norms in the Bangladeshi cultural context. Out of 45 Scarf injury patients in general, 44 of those were female, who are culturally and religiously expected to wear the long scarf. The cultural setting in this case is of great importance, as it influences the role and possibilities of disabled females living in their society. It was expected, that the female survivors would present with a more passive approach, adjusting to the situation that is presented to them, and often not actively raising their voices or demanding support. However, we also saw, in one case for example, that providing her daughter with education would be the only way to promote her independence and allow her to take care of her family, when the caretaker is elderly and unable to work anymore.

Those traditional norms, that the parents and female family members had to take care of the Scarf Injury patient, and thereby trying to restore the 'norm' in which the child will be able to provide for the parents at some stage, along with religious beliefs greatly influenced the coping and social reintegration successes. The role of belief and spirituality was a very prominent one throughout the interviews, yet varied to the extent

in influenced the coping mechanisms. In general though, we could see that a lot of power and trust of possible recoveries and happiness was placed on the wills of their respective gods. This perception however, was also emphasized during rehabilitation treatments, encouraging a sense of passiveness, further feeding into the role of the helpless victim.

On the other hand, that sense of not having any power over their situation, could have also had a positive impact on their mental health, believing in the possibility of recovery as well as not questioning the current situation. However, this passivity, which was emphasized by the caregivers and directly transferred to the Scarf Injury's behavior, led in many cases to a misconception of their abilities and possible level of function as well as independence. The cultural and religious norms have to be taken into account, when proposing policy changes and intervention programs.

The caregiver role, which in most cases were female family members, and their influence on the patient's wellbeing and coping strategies, has been evaluated before, however also needs to be seen in the cultural context. (Nogueira, Rabeh, Caliri, & Dantas, 2016; Paker, Bugdayci, Dere, & Altuncu, 2011)

Overall, mental health and life satisfaction were greatly impacted among all participants and their caregivers. However, it is to be noted, that the caregiver role, of mothers whose daughters were still in school age and living at home prior to the injury, was not questioned by the families. It was the mother's task to take care of her children. That

same sense of responsibility and expectation was also visible in the cases, where the survivors were already grown up, yet reconnected with their parents after the injury in order to have a caregiver. However, in those cases, the normal life course was disrupted, the mothers already being at an age, that they should be taken care of by their daughters, increased their level of stress and anxiety about the future.

Generally, the concept of one's future-self was very difficult for caregivers to describe. They generally were unable to identify their own needs and plans, but would respond in the caregiver role, expressing needs and goals for their family member. This neglect of one's own needs manifested as well in physical health complaints of caregivers, that if diagnosed, remained untreated or doctor's recommendations ignored, as this would interfere with the level of care they could provide for their family member.

Yet, that sacrificing nature would often further increase the feeling of being a burden and harmful member of the family in the Scarf Injury patients.

Several studies have quantified the Quality of Life in SCI survivors in various geographic locations and concluded a generally impaired Quality of Life in patients and caregivers, yet the expression of suicidal thoughts in one third of the study participants was striking. (Glickman & Neely, 2015; Unalan et al., 2001)

The severity of poor mental health and feeling of hopelessness emphasizes the strong need for better social and psychological support systems after surviving such a

traumatic event. The biggest challenge to implement realistic and efficient systems will be the scarce resources available in a lower middle income country like Bangladesh.

4.1 Implications for Policy and Practice

Based on our findings of the study, that demonstrate the severity and burden on the survivors, their families as well as communities from an emotional, social and ecological standpoint, we can conclude there are three main implications for future policies and improved practice.

1) Prevention of the Injury:

As stated by the participants as well as through communication with CRP staff, the injury itself is easily preventable, without the need for costly interventions. The safest way to prevent this injury is to fill the gap between the driver and passenger seat, however there is the need of centralized action by the government to implement those changes at the manufacturing stage. It is currently not possible to trace how many Easy Bikes are circulating, since no registration and licenses are required to operate those vehicles. (CRP, 2018). Another important aspect to prevent this injury is to educate and raise awareness about the possible risk of the Scarf Injury in the general population. CRP has already attempted several campaigns to address Easy Bike drivers as well as through a media campaign, however without the support of a nationwide campaign and

warning signs on Easy Bikes, led by authorities it will not reach the entire population at risk.

2) Education on Scarf Injuries and Spinal Cord Injuries:

That includes not only creating a knowledge base regarding risk factors, but especially educating healthcare providers, and the general population who might serve as first responders in the emergency management of Spinal Cord Injuries. We have been notified during conversations with CRP staff, that SCI are not part of the regular nursing curriculum in Bangladesh, emphasizing the gap of knowledge and abilities to manage SCI in the healthcare system. (CRP, 2018) The access and quality of care does not only include improving the capacities and treatment approaches of primary care clinics, but also avoiding catastrophic health expenditures. Those anticipated costs, if not already limiting the access to care completely, highly impacts the entire family and their abilities to provide for themselves long term.

The financial burden on the families can only be managed by healthcare reforms and acknowledging rehabilitation services as a substantial part of the healthcare system.

Additionally, by educating the communities about Scarf Injuries, but also SCI and persons who are living with disabilities, can facilitate the integration process, and limit stigma, or the perception of being 'othered' by the community. Some participants reported that the communities would ask hurtful questions, since they were the first wheelchair bound people, the community members have ever seen.

3) Psychological Support, Ongoing Long-term Rehabilitation Measures:

As mentioned previously, we believe that increasing the knowledge of the community can positively influence the participant's mental health, as it can increase the community's level of comfort to interact with them. On top of that however, we have identified a great need for ongoing psychological support of the survivors but also caregivers. Many participants reported to feel alone and helpless, and identified suicidal thoughts. We believe, that active coping mechanisms integrated in the rehabilitation process early on, as well as possible peer support groups for patients and their caregivers separately during CRP and possible after discharge could have a great impact on their mental wellbeing. (Boschen, Tonack, & Gargaro, 2005; Yao, Zheng, & Fan, 2015)

In order to assist in social reintegration as well as improving their mental health, being able to formulate future goals and having a perspective seemed to be one of the biggest protective factors. Therefore, we propose to make the return to school, or previous activities and especially perspectives of learning an income generating activity, the highest priority in the discharge planning of the patients.

In order to create a mindset of possible independence and return to parts of their previous life, the rehabilitation course and training of caregivers should focus primarily on teaching the family members to refrain from doing everything for their child. That promotion of independence early on, seemed to have a positive effect and created more

realistic visions of the patient's abilities as well as future goals, than those, who were told are unable to do anything.

Additionally, the high number of suicidal thoughts is alarming and requires immediate attention. However, in order to meet the needs of the patients and their families, counseling services need to be made available and integrated in the healthcare system. Despite their huge willingness, CRP is unable to provide ongoing services to all patients ever treated through their system, however has made female cervical SCI patients their priority in follow up care. Regardless of their impressive efforts, the task of implementing psychological care, following the biopsychosocial approach continuously is too big of a challenge for just one facility nationwide. It is necessary, that community services can be offered, that those families can be referred to.

4.2 Implications for Further Research

After having provided a first exploration of Scarf Injuries and the burden of female SCI survivors living in Bangladesh, the next research steps should include to further investigate the burden on the society. We assume, that the Scarf Injury patients presented at CRP only represent a fraction of the actual injury victims, given the amount of time, effort and money spent by most families until they received the care. One way

to conduct a prevalence study would be a hospital based registry or surveillance system of SCI and Scarf Injuries.

This surveillance system will be clinic based, therefore assuming, that all SCI patients will seek medical care after the injury takes place. However, given the severity of this type of injury, and reports of our participants, this is to be expected. Here, it would be crucial though, to include smaller primary care clinics, that might not be equipped to treat SCI patients, but are often the first point of contact between patients and the health care system, into the surveillance program. The sampling strategy therefore would be of great importance to find valid estimates of occurrences.

Having a surveillance system, or registry however, relying on the clinics to report each case, will still bear the risk of underreporting the prevalence. Since the injuries are usually that severe and shocking for many healthcare providers though, this could positively influence the willingness of the clinics to cooperate and report incidences in their facility.

Another logistical challenge would be, based on the data we could gather during the qualitative study with Scarf Injury survivors, is the double counting of cases. All interviewed participants reported to be referred and seen by multiple healthcare facilities, before having received treatment. Therefore, the same patient, who is being referred to several clinics, might be entered into the registry twice, if not integrating questions about referrals and person identifiable information in the registry.

A big advantage of setting up a facility based registry is, that we are having a direct access to educating healthcare providers on the acute care management of SCI, as previously mentioned in policy and practice implementations, which could greatly improve the patient's outcomes.

4.3 Study Strengths and Limitations

This study is of mainly qualitative nature, using only partially quantitative data from the patient's hospital records. Since the hospital data that we had access to, is secondary data, that was collected prior to the beginning of the study, we cannot assure its accuracy.

One limitation to the study is, that we could only conduct one home visit per family, and are using a screenshot of their wellbeing that particular day as the basis for our analysis. It could therefore be, that especially the emotional state that day was not fully representative of their status quo. However, to counteract that, we have ensured to spend several hours with each family, observing the family dynamics as well as including the caregivers' perspectives into our analysis. Additionally, the sample size itself of known Scarf Injury survivors is fairly small, yet we expect it to be highly underrepresented. However, based on the known sample size, we were able to interview a representative sample of the sample population. (See Table 3)

Nevertheless, we had only access to Scarf Injury patients, whose families were willing to invest in their female family member's wellbeing at a very high cost and eventually found their way to CRP. The fact that all adolescents were students before the injury, might also misrepresent the actual Scarf Injury population.

A strength of the study was, that the study team managed to create an environment for the survivors and their families to be heard and inspired to work towards regaining some independence.

5. Conclusion

This specific type of Scarf Injuries has not yet been described before and poses a great risk factor for life threatening and highly disabling injuries. However, this injury is easily preventable and policy changes to increase their safety should be put in place.

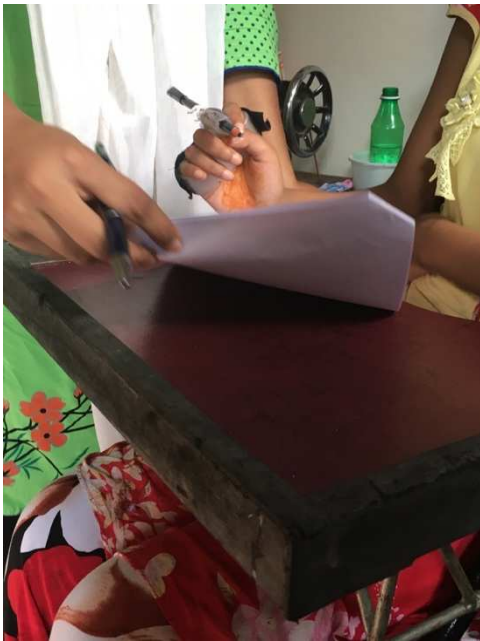
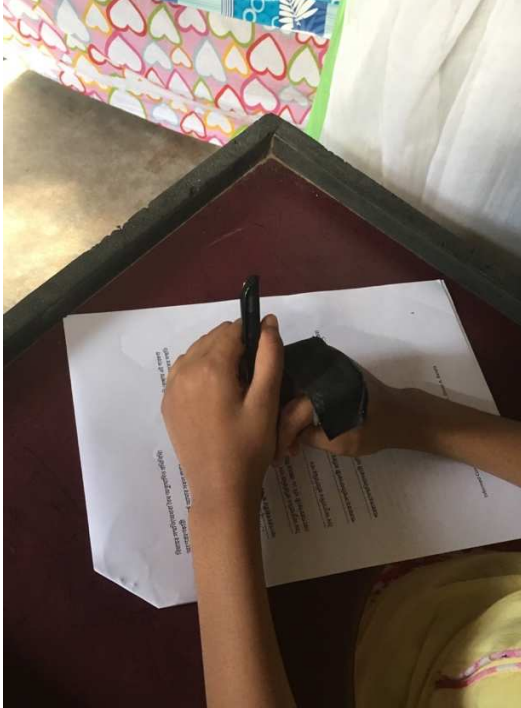
Additionally, increasing awareness and knowledge about SCI emergency care would likely improve long-term clinical outcomes. Moreover, greater competencies among providers for this unique mechanism of injury would increase the patient's and caregiver's level of understanding of their condition, and would begin the coping process. Disability is known to be a risk factor for living in poverty and social disadvantage, as well as poverty increasing the risk for disability. The phenomena of the Scarf Injuries presented in this Thesis appears to be no exception to that.

Living with a disability as a female in Bangladesh and other LMICs creates a double burden from the perspectives of patients, families and the community. The psychosocial component of the patient's rehabilitation as well as the caregiver burden deserve greater attention to promote physical and mental wellbeing.

Therefore, to improve health, mentally and physically, empowerment of the female survivors and targeted long-term rehabilitation aiming for successful social reintegration is necessary. Further studies are needed to identify effective and culturally sensitive intervention programs for females living with Scarf Injuries in LMICs.

Appendix A: Photographs

Assistive Devices



Accessibility



References

- Agrawal, A., Ninave, S., Srivastava, T., Sunkara, A., & Agrawal, S. (2009). Accidental unilateral and incomplete strangulation injury in a patient while traveling on a bicycle. *Journal of Forensic and Legal Medicine*, 16(6), 350-351. doi:10.1016/j.jflm.2009.01.004
- Alibaba.com. (2019). Eco Friendly And Good Price Easy Bike Electric For Bangladesh - Buy Easy Bike,Electric Auto Rickshaw,Easy Bike Electric Product on Alibaba.com. Retrieved from http://www.alibaba.com/product-detail/Eco-Friendly-And-Good-Price-easy_60267129006.html
- Bickenbach, J. (2011). The world report on disability. *Disability & Society*, 26(5), 655-658.
- Bickenbach, J., Officer, A., Shakespeare, T., von Groote, P., & WHO. (2013). International perspectives on spinal cord injury: summary.
- Boschen, K. A., Tonack, M., & Gargaro, J. (2005). The impact of being a support provider to a person living in the community with a spinal cord injury. *Rehabilitation Psychology*, 50(4), 397-407. doi:10.1037/0090-5550.50.4.397
- Bronfenbrenner, U. (1994). Ecological models of human development. *International encyclopedia of education*, 3(2), 37-43.
- Burns, A. S., & O'Connell, C. (2012). The challenge of spinal cord injury care in the developing world. *Journal of Spinal Cord Medicine*, 35(1), 3-8. doi:10.1179/2045772311Y.0000000043
- CRP (2018). [Personal Communication].
- CRP. (n/a). Centre for the Rehabilitation of the Paralysed, Website. Retrieved from <http://www.crp-bangladesh.org/>
- CRP-Bangladesh. (2013-2018). *Admitted SCI patients Dataset*
- George, E., & Engel, L. (1980). The clinical application of the biopsychosocial model. *American Journal of Psychiatry*, 137, 535-544.
- Glickman, L. B., & Neely, L. (2015). Home and community activity and participation status of clients with neurological disorders after rehabilitation center discharge in a less-resourced country. *Annals of Global Health*, 81(1), 220-221.

- Habal, M. B., Meguid, M. M., & Murray, J. E. (1972). The long scarf syndrome--a potentially fatal and preventable hazard. Report of 11 cases. *JAMA*, 221(11), 1269-1270.
- Jain, V., Agrawal, M., Dabas, V., Kashyap, A., Sural, S., & Dhal, A. (2008). Dupatta (scarf): a unique cause of cervical spine injury in females. *Injury*, 39(3), 334-338. doi:10.1016/j.injury.2007.09.008
- Khazaeipour, Z., Taheri-Otaghsara, S.-M., & Naghdi, M. (2015). Depression Following Spinal Cord Injury: Its Relationship to Demographic and Socioeconomic Indicators. *Top Spinal Cord Inj Rehabil*, 21(2), 149-155. doi:10.1310/sci2102-149
- Mallik, A., & Arefin, A. (2018). Micro Hybridized Auto-rickshaw for Bangladesh: A Solution to Green Energy Vehicle ~ Fulltext. *The Open Mechanical Engineering Journal*, 12,2018, 124-137. doi:doi:10.2174/1874155X01812010124
- Meara, J. G., & Greenberg, S. L. (2015). The Lancet Commission on Global Surgery Global surgery 2030: evidence and solutions for achieving health, welfare and economic development. *Surgery*, 157(5), 834-835.
- Meguid, M. M., & Gifford, G. H., Jr. (1972). The long free-flowing scarf--a new health hazard to children. *Pediatrics*, 49(2), 290-293.
- Mock, C. N., Jurkovich, G. J., nii-Amon-Kotei, D., Arreola-Risa, C., & Maier, R. V. (1998). Trauma mortality patterns in three nations at different economic levels: implications for global trauma system development. *Journal of Trauma*, 44(5), 804-812; discussion 812-804.
- Moniruzzaman, G. (2016). Easy-bikes cause traffic jam in Khulna. *The independent*. Retrieved from <http://www.theindependentbd.com/arcprint/details/34886/2016-02-23>
- Mugadlimath, A. B., Sane, M. R., Kallur, S. M., & Patil, M. N. (2013). Survival of a victim of Isadora Duncan syndrome: a case report. *Medicine, Science and the Law*, 53(4), 219-222. doi:10.1177/0025802413484141
- Nogueira, P. C., Rabeh, S. A., Caliri, M. H., & Dantas, R. A. (2016). Health-Related Quality of Life Among Caregivers of Individuals With Spinal Cord Injury. *Journal of Neuroscience Nursing*, 48(1), 28-34. doi:10.1097/jnn.0000000000000177
- Øderud, T. (2014). Surviving spinal cord injury in low income countries. *Afr J Disabil*, 3(2), 80-80. doi:10.4102/ajod.v3i2.80
- Paker, N., Bugdayci, D., Dere, D., & Altuncu, Y. (2011). Comparison of the coping

strategies, anxiety, and depression in a group of turkish spinal cord injured patients and their family caregivers in a rehabilitation center. *European Journal of Physical and Rehabilitation Medicine*, 47(4), 595-600.

Patel, P. A. (2011). Bioecological Theory of Development. In S. Goldstein & J. A. Naglieri (Eds.), *Encyclopedia of Child Behavior and Development* (pp. 247-249). Boston, MA: Springer US.

Peden, M., Scurfield, R., Sleet, D., Mohan, D., Hyder, A. A., Jarawan, E., & Mathers, C. D. (2004). World report on road traffic injury prevention: World Health Organization Geneva.

Rahman, A., Ahmed, S., Sultana, R., Taoheed, F., Andalib, A., & Yasir, A. (2017). Epidemiology of spinal cord injury in Bangladesh: A five year observation from a rehabilitation center. *J Spine*, 6(367), 2.

Sakran, J. V., Greer, S. E., Werlin, E., & McCunn, M. (2012). Care of the injured worldwide: trauma still the neglected disease of modern society. *Scandinavian Journal of Trauma, Resuscitation and Emergency Medicine*, 20, 64-64. doi:10.1186/1757-7241-20-64

Sezer, N., Akkuş, S., & Uğurlu, F. G. (2015). Chronic complications of spinal cord injury. *World J Orthop*, 6(1), 24-33. doi:10.5312/wjo.v6.i1.24

Singh, A., Tetreault, L., Kalsi-Ryan, S., Nouri, A., & Fehlings, M. G. (2014). Global Prevalence and incidence of traumatic spinal cord injury. *Clinical Epidemiology*, 6, 309-331. doi:10.2147/CLEP.S68889

Singh, P., Kumar, A., & Shekhawat, V. (2017). Scarf-related injuries at a major trauma center in northern India. *Chinese Journal of Traumatology. Zhonghua Chuang Shang Za Zhi*, 20(2), 90-93. doi:10.1016/j.cjtee.2016.03.009

Tumram, N. K., & Ambade, V. N. (2013). Fractured cervical vertebra in accidental strangulation by chunni. *Egyptian Journal of Forensic Sciences*, 3(3), 96-98. doi:https://doi.org/10.1016/j.ejfs.2013.05.001

UN. (2008). Article 1 - Purpose | United Nations Enable. Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html>

UN-ESCAP. (2012). Asia-Pacific governments launch a new Decade of disability-inclusive development | United Nations ESCAP [Press release]. Retrieved from

<https://www.unescap.org/news/asia-pacific-governments-launch-new-decade-disability-inclusive-development>

Unalan, H., Gencosmanoglu, B., Akgun, K., Karamehmetoglu, S., Tuna, H., Ones, K., . . . Tuzun, F. (2001). Quality of life of primary caregivers of spinal cord injury survivors living in the community: controlled study with short form-36 questionnaire. *Spinal Cord*, 39(6), 318-322. doi:10.1038/sj.sc.3101163

van Leeuwen, C. M. C., Post, M. W. M., van Asbeck, F. W. A., Bongers-Janssen, H. M. H., van der Woude, L. H. V., de Groot, S., & Lindeman, E. (2012). Life satisfaction in people with spinal cord injury during the first five years after discharge from inpatient rehabilitation. *Disability and Rehabilitation*, 34(1), 76-83. doi:10.3109/09638288.2011.587089

WHO. (2005). *Promoting mental health: concepts, emerging evidence, practice: a report of the World Health Organization, Department of Mental Health and Substance Abuse in collaboration with the Victorian Health Promotion Foundation and the University of Melbourne*: Geneva: World Health Organization.

WHO. (2011). World report on disability 2011.

WHO. (2012). Road traffic injuries. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/road-traffic-injuries>

WHO. (2013). Spinal cord injury - Key facts. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury>

WHO. (2014). How to use the ICF. *A Practical Manual for Using the International Classification of Functioning, Disability, and Health (ICF)*, 2013.

WHO, & ISCOS. (2013). *International perspectives on spinal cord injury*: World Health Organization.

Whoqol-Group. (1998). The World Health Organization quality of life assessment (WHOQOL): development and general psychometric properties. *Social Science and Medicine*, 46(12), 1569-1585.

Worldbank. (2017). Girls' Education Overview. Retrieved from <https://www.worldbank.org/en/topic/girlseducation>

Worldbank. (2019). Death rate, crude (per 1,000 people) | Data Bangladesh. Retrieved from <https://data.worldbank.org/indicator/SP.DYN.CDRT.IN?locations=BD>

Yao, T., Zheng, Q. Y., & Fan, X. C. (2015). The Impact of Online Social Support on Patients' Quality of Life and the Moderating Role of Social Exclusion. *Journal of Service Research, 18*(3), 369-383. doi:10.1177/1094670515583271