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RISK FACTORS FOR BURN CONTRACTURES IN LOWER INCOME COUNTRIES

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SUMMARY

Burns are a major cause of mortality and morbidity especially in low-middle income countries (LMICs). Burn contractures are particularly disabling and can occur in over 80% of burn survivors. Existing literature, predominantly from High-Income countries (HICs), demonstrates that risk factors for burn contractures are poorly understood, with little agreement on contracture definition or measurement. This study aimed to identify risk factors for burn contracture in LMICs to assist in future prevention strategies.

Potential risk factors were identified from the literature and a survey of 17 clinicians with extensive LMIC experience. LMIC sources emphasised socioeconomic considerations more than burn or treatment factors, which predominate in HIC studies. An observational cross-sectional study of 48 adult burn survivors with 126 major joints at risk was undertaken in Bangladesh to evaluate 48 risk factors at person and joint levels, with alpha set at 0.05 for comparative analysis.

At person level, employment status, self-discharge and fewer follow-up visits were associated with more severe contractures and greater movement loss. Full-thickness burns were associated with more severe contractures as was younger age at burn. Participants who knew about the risk of contracture development or received pressure treatment had less movement loss; refusal of skin graft was associated with greater movement loss. Joints which had pressure treatment had fewer contractures and grafted joints had less severe contractures. Anatomical location of the joint at risk also significantly affected contracture rates, with implications for the design of future risk factor studies.

This thesis presents the most comprehensive framework of contracture risk factors reported to date and reveals important differences between current LMIC risk factors and those in HICs. More work is required to improve whole person and joint outcome measures for accurate determination of risk factors for burn contracture. Recommendations for future research and clinical practice are made.

DECLARATIONS

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree

Signed:

Date: 1st November 2022

This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s). Other sources are acknowledged by footnotes giving explicit references. References are appended.

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LIST OF ABBREVIATIONS

ACT	Acuity Contracture Time
ADL	Activities of Daily Living
App(s)	An electronic application, usually downloaded by a user to a mobile device
AROM	Active range of movement
Bangla	Endonym for Bengali language used in Bangladesh
BCSC	Burn Contracture Severity Classification
BCSCj	Burn Contracture Severity Classification for a joint
BCSCp	Burn Contracture Severity Classification for whole person
BDT	Bangladesh Taka (currency)
BDT	Bangladesh Taka (currency)
BICU	Burns Intensive Care Unit
BMS	Burn Injury Model System National Database
CEO	Chief Executive Officer
CFU	Cutaneous Functional Unit
CSV	CSV is a delimited text file that uses a Comma to Separate Values
DALYs	Disability Adjusted Life Years
DART	Europe E-theses portal
DCT	Data Collection Tool
Delphi	A systematic and qualitative method of collecting information from experts using several rounds of questions
DMCH	Dhaka Medical College Hospital
DVT	Deep Vein Thrombosis
EBSCO	Elton B. Stephens Company
EQ5D	A family of instruments developed by EuroQuol used to describe and value health
EThOS	Database of all doctoral thesis awarded by UK Higher Education Institutions
Excel	Microsoft spreadsheet programme
FGD	Focus Group Discussion
FROM	Full range of movement
FTB	Full Thickness Burn
F/U	Follow Up
GCBIPR	The Global Centre for Burns Injury Policy and Research
GMEP	Group Music and Exercise Programme
GNI	Gross National Income

HIC	High Income Country (as defined by World Bank 2019)
HIV	Human Immunodeficiency Virus
HO	Hypertrophic Ossification
ICC	Intra-class Correlation Coefficient
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
ICU	Intensive Care Unit
ISOM	International Standards of Measurement
IQ	Interquartile range
ITU	Intensive Therapy Unit
Kms	Kilometres
Lakh	Bangladesh term for 100,000BDT
LL	Lower Limb
LMIC	Low- or Middle-Income Country (as defined by World Bank 2019)
LMS	Loss of Movement Score
LMSj	Loss of Movement Score for a joint
LMSp	Loss of Movement Score for whole person
LOS	Length of Stay
Max	Maximum
MDT	Multi-Disciplinary Team
Min	Minimum
Mod	Moderate (contracture)
MoH	Ministry of Health
N/No.	Number
NGO	Non-Government Organisation
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
NS	Not Significant
OATD	Open Access Thesis and Dissertations
ODK	Open Data Kit
OPD	Outpatient Department
OT	Occupational Therapy
Paed	Paediatric
PGT	Pressure Garment Therapy
PhD	Doctor of Philosophy (thesis)
Physio	Physiotherapy
PMH	Past Medical History
POP	Plaster of Paris
PPI	Patient and Public Involvement

PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROM	Passive Range of Movement
PROSPERO	The International Prospective Register of Systematic Reviews
PT	Physiotherapy
PTEX	Physiotherapy and Exercise
PUBMED	Free resource supporting search and retrieval of biomedical and life sciences literature
QoL	Quality of Life
RCT	Randomised Controlled Trial
Rehab	Rehabilitation
ROM	Range of Movement
ROM	Range of Motion
Rx	Treatment
SSG	Split Skin Graft
Safety Lit	Safety Literature - Injury Research and Prevention Bibliographic database
Scopus	Elsevier's abstract and citation database
SD	Standard Deviation
SHNIBPS	The Sheikh Hassina National Institute of Burns and Plastic Surgery
SPSS	Statistical Product and Service Solutions (statistical software by IBM)
TB	Tuberculosis
TBSA	Total Body Surface Area - calculated as a percentage according to standardised charts
UK	United Kingdom
UMIC	Upper Middle-Income Country (as defined by World Bank 2019)
UL	Upper Limb
US	United States
USA	United States of America
VTE	Venous Thromboembolism
Wi-Fi	Wireless Connection
WHO	World Health Organisation
Word	Microsoft document programme

1 INTRODUCTION

Burn injuries have been described as 'the forgotten global public health crisis' (Falder, 2014) and are a major public health problem (World Health Organisation, 2008).

Poverty and low socioeconomic status are associated with a higher incidence of burn injuries in both High-Income Countries (HIC) and Low or Middle-Income Countries (LMICs) (Golshan et al., 2013; Laverentieva, 2016; Peck, 2011; Peck & Pressman, 2013; Potokar et al., 2020), fundamentally lives lived in poverty increases the exposure to risk factors for burn injury. As such, burns are likely to be related to the non-medical factors that affect health outcomes i.e., the social determinants of health (SDH), (Khoo et al., 2022).

Adequate healthcare provision and access are also determined by the socioeconomic standing of the nation and injured individual (Feinstein, 1993; World Health Organisation, 2008). Lack of access to timely, specialised, and comprehensive burn care results in increased mortality and morbidity (Botman et al., 2021; Potokar et al., 2020). The incidence, mortality, and morbidity from burn injuries has reduced dramatically over the last 50 years in HICs, supporting the view that burn injuries and their sequelae are preventable. However, these shifts have not yet been mirrored in LMICs (Bailey et al., 2019; Potokar et al., 2020).

Ninety-five percent of global burn injury deaths now occur in LMICs (World Health Organisation, 2008). The rate of child mortality from fire and flames is nearly 11 times higher in LMICs than in HICs, with greater numbers affected by burn injuries than by TB and HIV (Peck, 2011). In Bangladesh, burns are the 5th leading cause of death in childhood (Mashreky et al., 2008a), while in

India, burns are the most common cause of death in women aged 15-35 (Sanghavi et al., 2001).

Due to the predominance of burn injuries in LMICs, this thesis focuses on burn injuries in lower income countries using the definitions outlined by the World Bank. The four country categories described are based on Gross National Income (GNI) per capita (Fantom et al., 2016). Countries can move up or down between categories, for the purposes of this thesis, the 2019 GNI per capita thresholds have been used (Netherlands for the World Bank, 2019). At that time the thresholds were <\$1,025 (low income), \$1,026-\$3,995 (lower-middle income), \$3,996-\$12,375 (upper-middle income) and >\$12,375 (high-income).

Death, disability, disfigurement, reduced quality of life, physical and psychosocial suffering may affect individuals following burn injury (Ali & Ali, 2022; Falder et al., 2009; Kelter et al, 2020; Lawrence et al., 2012). Burn injuries also affect survivors' families, communities and even the whole society, through the associated loss of productivity (Bailey et al., 2019; Mashrekey et al., 2008b; Peck et al., 2013). Burns are among the leading causes of disability-adjusted life-years (DALYs) lost in low- and middle-income countries (World Health Organisation, 2018).

The most common morbidity post-burn is dermal scarring. Deeper burns heal by repair rather than regeneration of the skin; the complex interactions involved in recovery of the wound replace the normal skin cells with more fibrous scar tissue (Marshall et al., 2018). The longer the healing time (which can be considerably shortened through skin grafting), and the greater extent of dermal loss, the more severe the scarring expected (Finlay et al., 2017). Scarring can significantly alter the appearance of an individual, have profound

psychosocial implications and reduce quality of life (Peck, 2011; Serghiou et al., 2016).

One of the most physically limiting consequences of burn scarring is the limitation of movement at a joint or the deformation of a feature, called a burn contracture. The review of the literature presented in Chapter 3 reveals a lack of consensus on contracture definition, however the definition selected for this study was “an impairment caused by skin with pathological scar tissue of insufficient extensibility and length, resulting in a loss of motion, or tissue alignment of an associated joint or anatomical structure” (Richard et al., 2009, p. 544). The operationalisation of this definition was developed through the process of this study and is presented in section 5.5.1.1. The extent or severity of a contracture can vary considerably, from minimal loss of movement with no functional impact to total obliteration of a joint/feature movement and severe disability and disfigurement. There is no consensus in the literature on the best classification of contracture severity (Schouten et al., 2021). In this study, two methods of classification have been used (one categorical and one continuous), these are described in section 5.5.1. Figure 1-1 illustrates the appearance of a burn contracture. The knee contracture (Figure 1-1) was classified as mild and the elbow contracture as severe, according to definitions used in this study to quantify contracture severity (described in section 5.5.1).

Contractures can be painful, reduce the ability to function due to tightness and limited range of movement, cause altered appearance, reduce quality of life, and have psychological consequences (Ahuja et al., 2016; Cabulon et al., 2015; Gauffin et al., 2015; Hendriks et al., 2021, Iyer & Soletti, 2021; Koljonen et al., 2013; Lawrence et al., 2013; Spronk et al., 2018), resulting in individuals withdrawing from their usual social interactions, and limiting work opportunities (Peck, 2011).

Figure 1-1: Typical burn contractures in the LMIC setting



Burn care is very expensive (Poudel et al., 2021) and in contexts where individuals must cover some (or all) costs themselves this expense, added to the loss of productivity from the injury, burns can drive individuals and families, already likely to be poor, deeper into poverty (Mashrekey et al., 2008b).

The optimal treatment of burn injury requires input from patients, their carers, and a full multidisciplinary burn team. Scar reduction is a major component of surgical, nursing and rehabilitative treatment. Many of these interventions are required throughout scar maturation, which can take up to two years post-injury (Kant et al., 2018). Unresolved contractures require later stage surgical release to increase comfort, movement, and aesthetic acceptability. Contracture release accounts for a high proportion (some estimate 50%) (Saaiq et al., 2012) of a plastic surgeons' workload in LMICs. However, this is likely to represent the tip of the iceberg in terms of contracture morbidity (Muguti & Mhaka, 1994) as the capacity for reconstruction of contractures is very limited in LMICs (Botman et al, 2019).

Authors in published literature frequently describe contractures as being completely preventable (Ibrahim & Asuku, 2014; Puri et al., 2019), other

statements of contracture preventability are qualified on the availability of effective burn care (Hudson & Renshaw, 2006). Other authors suggest that contractures are not preventable even with the best care (Goverman et al., 2017; Oosterwijk et al., 2017; Schneider et al., 2006). This is supported by data from 13 specialist burn centres in the USA (where one would expect a high quality of care), the study reported a contracture prevalence rate of 82% on discharge (Richard et al., 2017).

There is little evidence in the literature to compare prevalence rates of contractures between HICs and LMICs. Different environments, definitions of contracture and measurement time-points contribute to the variations amongst studies. The small number of studies from LMICs contributes to difficulties in quantifying the problem.

Without adequate knowledge of risk factors, contracture prevention is likely to be suboptimal and ineffective. Common cited risk factors for burn contracture formation are depth of burn, large total burn surface area (TBSA%), skin grafting, and lack of therapy interventions such as pressure and splinting (Dobbs & Curreri, 1972; Gangemi et al., 2008; Godleski et al., 2018; Oosterwijk et al., 2017; Schneider et al., 2006). However, there is a surprising lack of robust evidence on risk factors, and little is known about interactions between, or relative potency of different risk factors. Research into risk factors from LMICs is particularly lacking, despite the high incidence of burns and contractures in these regions.

The author developed an interest in this topic from her physiotherapy experience in both HIC and LMIC burn care, which led to the observation that burn contractures appeared to be considerably more common and severe in LMIC patient populations. This observation stimulated the present study, the aim of which is to contribute to knowledge on risk factors for burn

contractures in LMICs with the ultimate purpose of informing future prevention efforts by focusing on the question:

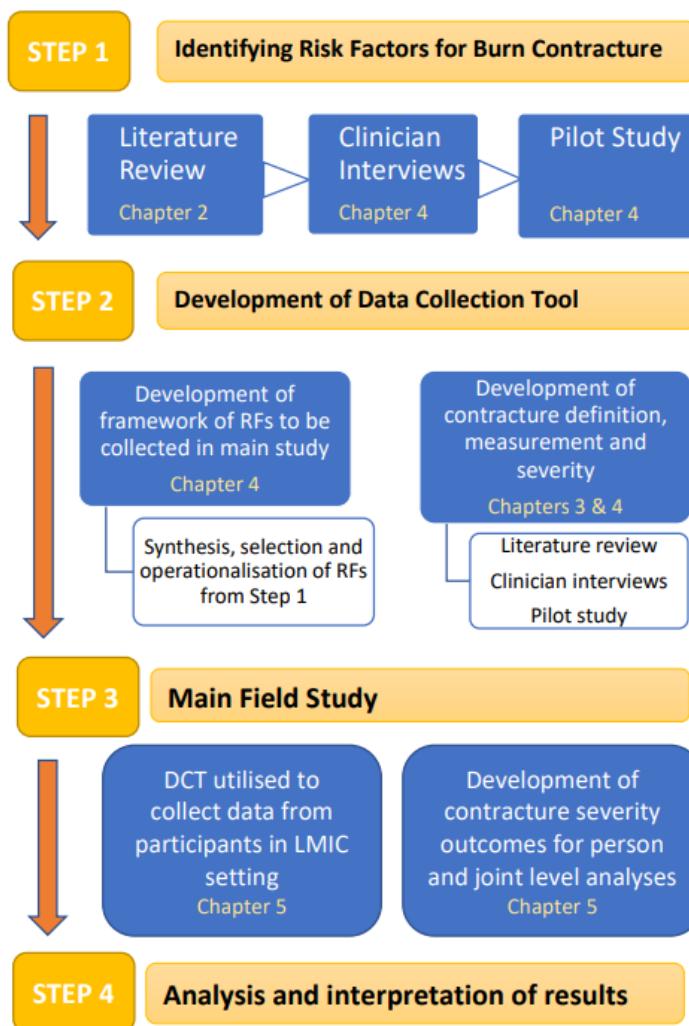
What are the risk factors for burn contracture formation in lower income settings?

To address this, the first task was to conduct a detailed literature review of all current knowledge on risk factors for burn contracture. The findings of this review of relevant literature are presented in Chapter 2. The focus of the review was on potential (actual or postulated) risk factors for contracture in both HIC and LMIC environments.

Chapter 3 discusses the rationale for the research methods selected for the subsequent primary study, including the study design chosen, the approach used to collect data on risk factors and the methods employed to define and quantify contracture. Chapter 4 explains the development of the data collection tool (DCT) used in the final study, including a small study in which burn care professionals working in LMICs were interviewed to gain their opinions on risk factors in LMIC settings. The DCT was further refined following a pilot study, also reported in Chapter 4.

Chapter 5 outlines the Methods for the primary data collection and analysis of the results from the main study, which took place in Bangladesh in October/November 2019. The final study methods were the product of an extensive process of development, which is described in Chapters 2-4 and illustrated schematically in Figure 1-2 below.

Figure 1-2: Schematic representation of steps in determining main study methods



Chapter 6 presents descriptive statistics for the study participants and their joints at risk. Chapter 7 describes analyses of risk factors at whole person and joint level.

Chapter 8 discusses the findings of the present study in relation to the research aim, objectives, and existing literature. Limitations of the methodological approach selected, and the findings are considered. Key achievements of this work, and implications for contracture prevention are described. Recommendations for future work in this field are suggested in Chapter 9. Chapter 10 concludes the thesis.

2 LITERATURE REVIEW

2.1 INTRODUCTION

A review of the literature was conducted to identify the existing evidence for risk factors for burn contracture formation. This chapter starts with a definition of key terms relevant to the literature search, followed by the method used to execute the search and an overview of the literature identified. The remainder of the chapter reviews the literature in detail, according to the types of publication, categorised as systematic reviews, studies specifically designed to identify risk factors for presence and/or severity of contracture (termed risk factor studies), descriptive studies, interventional studies, and putative (i.e., commonly accepted or supposed) risk factors. The final section provides an overall summary of the risk factors identified and outlines the objectives for the rest of the study.

2.2 DEFINITION OF TERMS

2.2.1 Risk

The definition of a risk factor which underpins this review is:

“any factor that is considered to increase the probability of an adverse outcome”

(Kraemer et al., 2005 as cited by Shenderovich et al., 2016).

The adverse outcomes considered are the presence and severity of a burn contracture. Factors that were identified as protective against contracture formation were also included as they increase the probability of a positive outcome; often protective factors are the converse of adverse factors.

A very broad net was cast in examining the literature in terms of what might constitute a risk factor. In addition to research papers, it was considered important to include published clinical opinions on factors that are commonly

accepted to impact upon the presence and severity of a contracture; these are described as 'putative risk factors'.

Inherent to identification of a risk factor is that the risk must precede the outcome (Burt, 2001; Offord & Kraemer, 2000). A contracture may appear, resolve, worsen, or improve during scar maturation, which is normally considered to be a two-year process (Kant et al., 2018). Children may develop a contracture beyond this time due to the impact of growth. At some point in time a contracture in an adult patient will become 'fixed' (at or before completion of the scar maturation process). At this point, the contracture will not deteriorate or, without surgical intervention, improve. Literature on 'fixed' contractures would deliver a very limited literature review. For this study, a risk factor was considered influential on a contracture whether that contracture is still in the process of maturation (i.e., could improve or worsen) or not. This is important for treatment interventions, as such factors may be both prophylactic or used to 'treat' a contracture. For example, a contracture may already be present, but if an intervention is initiated soon enough, the contracture may resolve, whereas without that intervention the contracture could remain or worsen. Consequently, *lack* of an intervention may also be considered a risk factor.

A risk factor and a causal factor can be differentiated in that a cause must always contribute to the outcome (Beaglehole et al., 1993; Parascandola & Weed, 2001). Lack of splinting may be a risk factor, as it is possible to have had a splint and still develop a contracture; lack of splintage itself cannot be a cause of contracture. The language around 'risk' and 'cause' in the burn contracture literature is diverse, inconsistent, and often misleading. Many words other than 'risk' are used to explain a factor that is considered to increase the probability of an adverse outcome; these terms are included in the search

terms (Table 2-1). In the literature, the term ‘cause’ is often used interchangeably with ‘risk factor’.

Within the burn literature there is no standardised approach to the identification or classification of risk factors, nor has a framework to identify risk been established. Risk factors identified from the literature from both HICs and LMICs are presented; in every section the origin of factors, whether HIC or LMIC, is highlighted.

2.2.2 Contracture

A burn contracture is a loss of movement at a joint or the deformity of a structure due to scarring following a burn injury (Oosterwijk et al., 2017; Schouten et al., 2021). This literature review does not include papers that describe single joint contractures of the face, hand, toes, perineum or breast. Although these are areas where deformity from scarring can be very disabling, for the purposes of this study the term ‘contracture’ is only used to indicate loss of movement (or function) of a joint.

There is no accepted or standardised operationalised definition of a burn contracture (Oosterwijk et al., 2017) so papers with any reference to contracture were included even where no definition of the term ‘contracture’ was given. Occasionally the term ‘disability’ was used; if the disability could be determined to be the result of a burn contracture, the term was accepted as an outcome of interest. If the reported outcome was loss of range of movement (ROM), but the term ‘contracture’ was not used, the study design and context was considered and if contracture was the likely cause of the loss of movement, this publication was included. Not all loss of range can be attributed to a contracture, especially in the earlier stages of a burn injury. If there was ambiguity as to whether the loss of range represented a contracture, this was noted in the review of the paper. In papers which focus on patients

with established burn contractures, the requirement for contracture release was taken to infer the presence of a contracture.

How contractures are defined and measured has an impact on subsequent identification of risk factors, therefore the methods of definition and measurement of contracture were noted for all publications reviewed.

2.2.3 Burn Factors

This section covers the key terms used in the literature on burn-related risk factors.

The term 'cause' of burn is used to indicate the substance causing skin injury, commonly categorised as flame, chemical, scald (e.g., hot water), electrical and contact (with a hot surface). 'Mechanism of burn' refers to the nature of the incident which led to the burn e.g., an explosion of a gas cylinder.

The extent of a burn is often described using the total body surface area affected (TBSA). TBSA can range from <1% to 100% of the body surface; the higher the TBSA, the more extensive and severe the burn injury and worse the prognosis may be. There are established methods of calculating the percentage area of burn, which differ for children and adults due to the variation of body proportions between the two (Giretzlehner et al., 2013).

'Depth of a burn' refers to which layers of the skin have been destroyed by the burn injury; current categories are 'superficial', 'partial thickness' (superficial or deep partial) and 'full thickness' (Benson et al., 2006). Previously, the terms 'first', 'second', 'third' and 'fourth-degree' burns were used (Kearns et al., 2013). The terms 'superficial' and 'first-degree' burn are synonymous and involve destruction of the epidermis only. A second-degree burn is similar to a partial thickness burn. A third degree or full thickness burn inflicts damage to all layers of the skin. Layers beyond the skin, such as fascia, are involved in a fourth-degree burn. As both classifications appear in the literature, the

system used in each paper is provided in the review. There is a correlation between the depth of burn and scarring (Chiang et al., 2016), with deep burns producing more scarring and potentially more contracture, depending on the location of the scar.

An ‘inhalation injury’ is usually caused by smoke or toxic fumes from a flame burn, but also can result from ingestion of a hot substance or chemical. The presence of an inhalation injury can worsen the prognosis of the burn injury (Palmieri, 2007; You et al., 2014).

The classification of ‘paediatric’ and ‘adult’ age groups varies in many studies, depending on the country of origin, ranging from 14 to 19 years. In this review, the term ‘adult’ is used if the patient is 18 years or older, or the age classification of the publishing author is used.

Study populations are also often described as ‘acute’ or ‘reconstructive’. ‘Acute’ burn patients are patients with recent burn wounds which are not yet healed. ‘Reconstructive’ patients are those presenting for surgical management of their burn contractures after acute care/hospital discharge.

The nature of burn care may also influence burn contracture presence and severity; this is globally diverse and often not well-described in the publications included in this review. Burn care is ideally multidisciplinary but is often of varying standards (especially when comparing HIC and LMIC settings) and can be difficult to define. In many HIC countries, burn care is standardised and regulated, so variation between institutions is more limited. However, in LMIC burn care, most burn patients may not receive care in specialist burn centres; this gives rise to greater variation and may reduce the quality of the care necessary for effective burn treatment. In addition, the health systems in LMIC settings may not be able to offer comprehensive care; patient income, location and other socioeconomic factors influence healthcare

access. Specific treatments that are now considered essential for optimal care in HIC may be varied in LMICs. For example, lack of reported physiotherapy care in some studies may mean there was no physiotherapist, or only limited availability of interventions, or delayed or minimal physiotherapy input. The burn care available to the study population will affect the number and diversity of risk factors that can be explored.

2.2.4 Treatment Factors

The term ‘skin graft’ refers to surgical coverage of a wound using skin from another site. Skin grafts can be full or split thickness, the grafts referred to here are split skin grafts unless specified. Meshed, fenestrated or sheet grafts refer to whether the graft has been applied as a sheet or with fenestrations or meshed.

Positioning refers to placing the joints in established ‘anti contracture’ positions, opposite to the contracture that most commonly develops at that joint i.e., elbows usually contract into flexion, therefore elbows are positioned in full extension. Positioning is initiated immediately post-admission, for a variable duration.

Splinting refers to fixing a joint in position by the use of an external solid material such as plastic, plaster, thermoplastic. Splints are used to prevent or treat a contracture. Splints are usually applied in ‘anti-contracture’ positions. Splinting can be applied at various times and for various durations; they are mostly used in the acute phase of burn care.

‘Pressure’ treatment/therapy refers to the use of firm elasticized garments which apply a constant pressure to the skin to reduce hypertrophic scarring. The pressure garments are applied once the burn wound has healed and are

made specifically for each patient; they require follow-up to maintain the fit and are often worn for up to 2 years post burn.

2.3 METHOD

The literature search included publications available through electronic search tools up to June 2019. This time limit was necessary as the results of the literature review were needed to inform the range of risk factors to be explored in the planned primary data collection, for which ethical approval was required by June 2019. Relevant publications after this date, but prior to thesis submission, have been included in the Discussion (Chapter 9).

2.3.1 Search Databases

The terms presented in Table 2-1 were used to search the following databases:

1. Cumulative Index to Nursing and Allied Health Literature
2. Medical Literature Analysis and Retrieval System Online
3. PUBMED
4. Scopus
5. Web of Science
6. Safety Lit
7. Cochrane
8. PROSPERO
9. EThOS
10. EBSCO – thesis finder
11. ProQuest dissertation and thesis
12. DART Europe E-theses portal
13. Open Access Theses and Dissertations (OATD)

2.3.2 Search Terms

Table 2-1: Terms used for literature searches

Burn AND	Contracture AND	Risk
MH Burn or Burn*	Contracture* or “range of mo*”	risk* or caus* or profile* or predict* or epidemiol* or factor* or influenc* or determin* or contribut* or predispose* or prevent* or outcome*

2.3.3 Inclusion and Exclusion Criteria

All papers which reported on factors influencing burn contractures were included in the search, including all causes of burns in all age groups. No date filter was used. Non-English abstracts were manually filtered because many abstracts were in English even if the full text was not. This enabled a broader view of the literature, and any key articles on the topic, especially if from a LMIC source, could be translated if necessary.

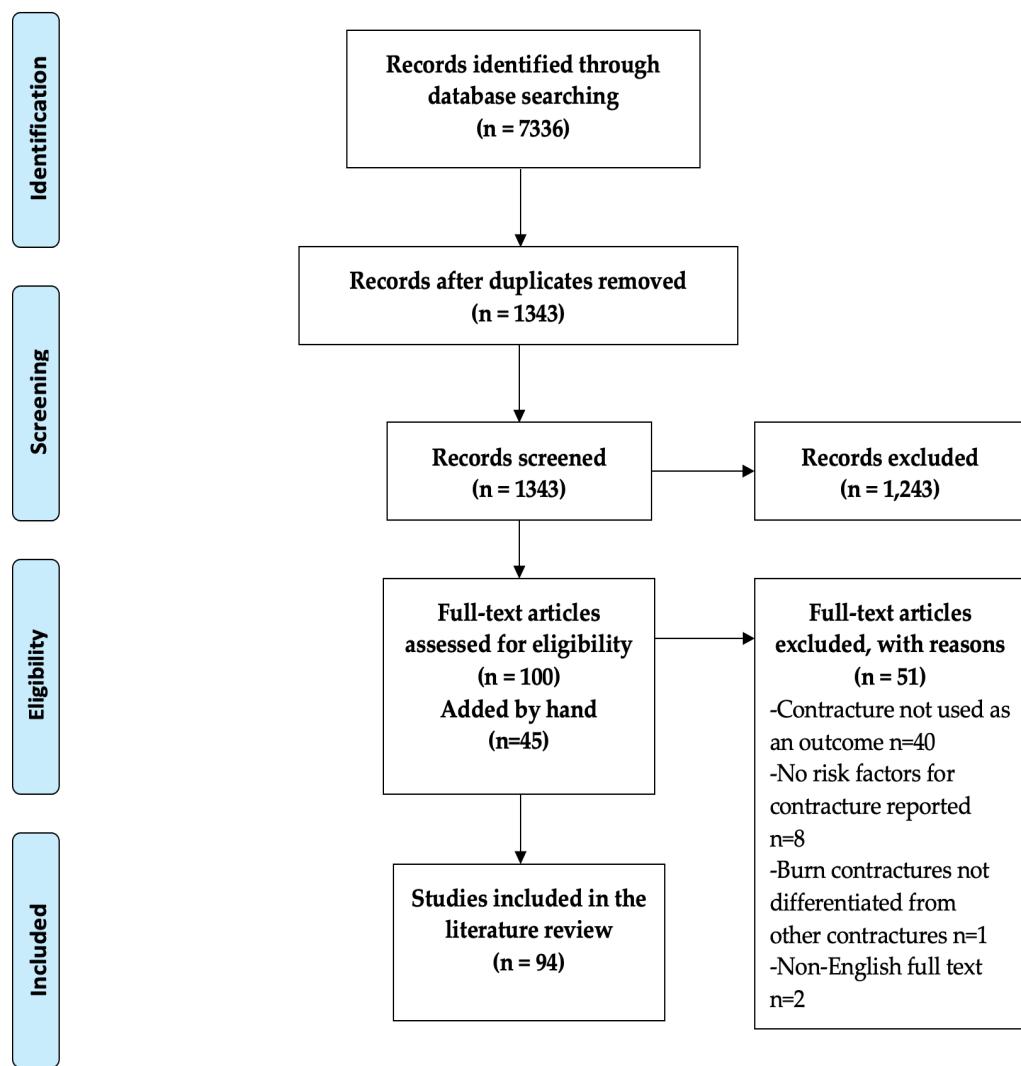
The following publications were excluded:

- Contractures not caused by burns, including if burn contractures were mixed with non-burn contractures and results could not be differentiated
- Contractures related to a burn injury but not as a direct result of burn scarring, such as heterotopic ossification, Volkmann's contracture, peripheral nerve damage
- Reports of non-acute surgical management of contractures (burn reconstruction) or any other treatment given to fixed contractures that did not include a description or statistical analysis of any risk factors which may have caused the contracture
- Reports of contractures only of single non-major joints which were not included in the primary study, (i.e., hands, face, perineum, breasts, toes). Papers including these features/joints along with major joints were included
- Reports on wound contraction or cellular level contraction
- Animal studies

2.3.4 Search Results

A summary of the number of papers found, papers excluded and those reviewed is presented in Figure 2-1. Only three papers selected for full text review could not be accessed. Ninety-four papers were finally included in this review. Fifty-one papers were excluded after accessing the full text article.

Figure 2-1: PRISMA chart



2.4 OVERVIEW OF THE LITERATURE

This section gives a brief overview of the literature as a context for the more detailed review of the publications which follows.

2.4.1 Year of Publication

No date limits were set. The earliest paper included was published in 1932 and the most recent was published in June 2019.

2.4.2 Category and Type of Publication

As this was not a systematic review of the literature, no specific quality assessment tool was used to appraise papers, however each publication reviewed was individually critiqued in detail with respect to methodology, data analyses and interpretation. The literature review was focussed on identifying any potential contracture risk factors which have been described whether evidence-based or putative. The structure chosen for presenting the risk factors considers levels of evidence (Guyatt and Sackett, 1995) in the ordering but does not fully follow it to enable the presentation of risk factors along with the context in which they were identified. The papers identified were of widely varying types and have been divided into five categories: systematic reviews, risk factor studies, descriptive papers, intervention studies and papers reporting putative risk factors (Table 2-2). For completeness, published PhDs were also searched. Details of the types of papers included in each category are given at the start of each section. The number of papers in each category, by HIC or LMIC source, are listed in Table 2-2.

Table 2-2: *Number of publications reviewed by category and origin*

Category	HIC	LMIC	Total
Systematic reviews	2	-	2
Risk factor studies	12	3	15
Descriptive	4	9	13
Interventional	17	-	17
Putative	37	10	47
TOTAL	72	22	94

2.4.2.1 Systematic reviews

Before reviewing individual studies, section 2.5 presents relevant published systematic literature reviews. There were no published systematic reviews from LMIC settings.

2.4.2.2 Risk factor studies

These papers frequently used inferential statistical methods such as odds ratio, uni/multivariate analysis, logistic regression and tests for statistical significance to identify risk factors. These papers reported contracture as an outcome of general burn care and explicitly aimed to explore risk factors for burn contracture formation. Three of the fifteen articles in this section are from LMIC.

2.4.2.3 Descriptive studies

This category is the most common type of publication from LMICs, while HIC publications dominate all the other categories of papers. These papers use descriptive statistics to outline a population and the burn care provided and include contracture as an outcome (usually amongst other outcomes). These reflect the scenarios seen by the authors (all of whom were clinicians) and could arguably generate putative risk factors for contracture formation, which may subsequently be included in other publications.

2.4.2.4 Intervention studies

Papers reporting the impact of a specific intervention(s) which used contracture as an outcome were included in this category. All of these interventions are therapy-related, such as splinting or exercise. Literature reviews relating to specific interventions are also included here. These papers are differentiated from the systematic literature reviews referenced in section 2.8.2 which address general risk factors for burn contracture. Three of the 17 papers in this section are from Iran and China; these are Upper-Middle Income Countries (UMICs) as determined by the World Bank (Netherlands for the World Bank, 2019).

2.4.2.5 Putative risk factors

These are publications that may address any topic within burn care but reported one or more assumed risk factors within the publication; this was often just a sentence or an introductory statement. The vast majority of papers in this section are from HIC contexts.

2.4.2.6 PhD theses

A search of available PhD theses via national and international databases found three PhDs on burn contracture. One was on the impact of a topical drug on burn contracture, but this PhD is in embargo until 2024. Another was focused on measurement of hypertrophic scar rather than contracture and on surgical options for scar and contracture (Van de Wal, 2013); as such it was not considered to be relevant.

The third was relevant; the PhD was titled “From range of motion to function – loss of joint flexibility after burns: when is it a problem?”. This was a European PhD via publication, comprising 5 articles which were published separately (Oosterwijk et al., 2017; Oosterwijk et al., 2018; Oosterwijk, Nieuwehuis, Schans et al., 2019; Oosterwijk, Nieuwehuis, Schouten et al., 2019). Three of these articles are relevant and reviewed within this thesis.

2.4.3 Study Populations

The sample sizes of included studies ranged from two (Muguti & Mhaka, 1994) to 2,559 (Kowalske et al., 2003). Both acute and reconstructive burn patients are included in the studies reviewed. Most LMIC studies involved both children and adults, but HIC studies tend to separate children and adults; most refer to adult patients. The majority of studies are hospital-based and concern acute burn patients; only one study (from a LMIC) collected data at the community level. Several studies from HIC settings used multi-centre databases for data collection; no LMIC studies report results from regional or

national databases and there are no LMIC studies which utilise data from more than one centre. Most LMIC studies collect data directly from patients/carers by interview.

2.4.4 Authorship

The total number of papers from HICs was 72, with 22 from LMICs (Table 2-2). All but one of the papers included in this review were authored by healthcare clinicians, the exception being that by Fergusson et al. (2017) for which the first author was a public health practitioner and researcher. All papers written from LMIC sources were written by medical doctors. The HIC studies also have a predominance of medical authors but include some physiotherapists.

2.5 SYSTEMATIC REVIEWS ON RISK FACTORS FOR BURN CONTRACTURE

Six systematic reviews were identified. Only two were specific to general risk factors for contracture formation (Fergusson et al., 2007; Oosterwijk et al., 2017). The earlier publication is a review of all types of contractures rather than specifically burn contractures (Fergusson et al., 2007). The more recent review primarily addresses the prevalence of burn contractures but also reported findings on the determinants of burn contractures (Oosterwijk et al., 2017). Both reviews are from HICs - Canada and the Netherlands respectively.

Four additional systematic reviews reported the effectiveness of physiotherapy interventions, such as stretch or exercise, on contractures (and other outcomes), rather than evaluating a wider range of risk factors (Flores et al., 2018; Harvey et al., 2017 Katalinic et al., 2008; Zhang et al., 2017). These four reviews are discussed in the Intervention Section, 2.8.

Fergusson et al. (2007)

This systematic review looks at the epidemiology of major joint contractures and was the sole contributor of burns patients to a 2008 Cochrane review by Katalinic et al. (2008). From 1875 papers identified by Fergusson et al, only 19 met the final inclusion criteria for the review, with one study on burn contractures (Huang et al., 1978).

The results of the study by Huang et al. (1978) are presented in the review, giving the population size (625 patients) and rates of burn contracture in 4 major joints for patients treated with/without splints and/or pressure. This paper was independently identified by the literature search for the present study, as it relates to the effect of a single therapeutic intervention (splinting) and is discussed with the intervention papers.

Fergusson et al. (2007) concluded that despite reports of the high prevalence and significant negative impact of contractures on quality of life, the “epidemiology of joint contractures across many vulnerable populations remains unknown” (p.29). The importance of accurate and specific definitions to capture prevalence and determinants was highlighted, as was the lack of definition and measurement of contracture in most studies. Fergusson et al. (2007) gave examples of three different definitions of ‘contracture’ and stated, “Clearly, different definitions lead to different epidemiological measures. Standard definitions are necessary to reduce misclassification bias and for comparing measures across populations” (p.28). This statement is equally applicable to studies of risk factors for burn contractures.

Oosterwijk et al. (2017)

In their systematic review of prevalence and determinants of burn contractures, Oosterwijk et al. (2017) noted at the outset that there was “no accepted definition of contracture” (Oosterwijk et al., 2017, p. 42) so they

included all reports of contracture. Of the ten papers included, only 2 were from a LMIC (Nigeria). The authors used a quality tool for the reporting of prevalence studies (Munn et al., 2014); none of the 10 papers included was deemed to have met all six of the quality assessment criteria required, and only one (Schneider et al., 2006) met 5/6 quality indicators. Only 7 papers were deemed to provide sufficient data to address determinants of contracture; all 7 were from HICs (Dobbs & Curreri, 1972; Gangemi et al., 2008; Huang et al., 1978; Kidd et al., 2013; Kowalske et al., 2003; Pegg et al., 1979; Schneider et al., 2006).

All 10 papers included in this review were also identified by the literature search for this thesis and are reviewed in more detail in subsequent sections of this chapter. The risk factors for contracture identified from the systematic review were:

- Younger age (Gangemi et al., 2008; Kidd et al., 2013; Kowalske et al., 2003)
- Gender - females were at greater risk in two studies (Gangemi et al., 2008; Pegg et al., 1978;) and males in another (Kowalske et al., 2003)
- Ethnicity – Hispanics were more at risk in <18 yr olds, blacks were more at risk in 18-60 yr olds (Kowalske et al., 2003)
- Aetiology – Flame burns were a greater risk (Gangemi et al., 2008; Kowalske et al., 2003)
- Greater TBSA (Dobbs & Curreri, 1972, Gangemi et al., 2008; Huang et al., 1978; Kidd et al., 2013; Kowalske et al., 2003; Pegg et al., 1978; Schneider et al., 2006)
- Greater burn depth (Dobbs & Curreri, 1972, Gangemi et al., 2008; Pegg et al., 1978; Schneider 2006)
- Longer length of stay (Schneider et al., 2006)
- Site of burn – (Dobbs & Curreri, 1972, Gangemi et al., 2008; Huang et al., 1978; Kidd et al., 2013; Kowalske et al., 2003; Schneider et al., 2006)

In some cases, the summaries appear to be misleading or misreported. For example, the authors reported that Pegg's (1978) study showed that females had a significantly higher incidence of contractures than males, however the Pegg (1978) paper is a descriptive study with no tests for statistical significance and therefore use of the word 'significantly' may be misleading. In the Dobbs & Curreri (1972) paper, shoulder contracture incidence is reported as 54%, but is reported as 4% in the systematic review; possibly this was a print error.

Oosterwijk et al. (2017) did not report the methodologies used for calculating individual joint contracture rates, so it is possible that reported prevalence rates in individual anatomical joints are affected by how a 'joint at risk' is defined; as with contracture itself, there is no consistent definition of what constitutes a 'joint at risk'. The issue of timing of assessment for contracture after burn was not discussed in the systematic review. The review concludes that prevalence of contracture may be high at the time of hospital discharge, but lower after a longer period.

The review also comments that some treatment modalities may reduce the prevalence of contracture; they refer to the paper by Huang et al. (1978) on the efficacy of splinting which reported a much lower frequency of contracture after 6 months of splinting. Given the natural impact of time on contracture prevalence noted in this review, the timing as well as the nature of therapeutic interventions may affect the outcome.

Oosterwijk et al. (2017) stated as their primary conclusion that

"The prevalence of scar contractures after burn is insufficiently reported and varies considerably between studies. When prevalence is unclear, it is also difficult to investigate potential determinants and to evaluate changes in interventions" (p.47).

This highlights the difficulties facing researchers attempting to identify risk factors for burn contractures, especially in LMICs; achieving properly controlled, longitudinal, long-term studies in such environments will be extremely difficult.

2.6 RISK FACTOR STUDIES

Fifteen publications using more robust analyses to identify risk factors for contracture development were identified. These articles look at the whole framework of care and not specific treatment interventions, which are covered in section 2.8. There were 9 papers from HIC centres and 3 from LMIC settings (Ghana 2, Nigeria 1). Two publications identified were conference abstracts and one was a Letter to the Editor in relation to another publication; this letter also included re-analysis of original data from the authors. Both abstracts and the letter were from authors in HIC centres.

The nine HIC papers were published between 1988 and 2019, but the majority (7/9) were published during the last decade. All but one were multicentre publications originating from North America (6), the Netherlands (2) and Wales (1). A single-site retrospective analysis of prospectively gathered data was published by authors from Italy (Gangemi, 2008). All but two of the North American papers were from authors in the same centres, as were both the Dutch publications. Therefore, the data presented and analysed emanates from only 5 institutional groups. Additionally, the published letter (Richard et al., 2013) and one of the two published abstracts (Richard et al., 2015) came from the same author group in the US Army; the second published abstract (Kowalske et al., 2003) came from the same group of North American institutions as 4 of the full papers (Godleski et al., 2018; Goverman 2017a; Goverman 2017b; Schneider et al., 2006). The studies by Kowalske (2003), Godleski et al (2018) and Goverman (2017a and 2017b) all reported data from

the Burn Injury Model Systems National Database (BMS) which was set up in 1994 and is funded by the [National Institute on Disability, Independent Living, and Rehabilitation Research \(NIDILRR\)](#). Four federally funded clinical burn centres provide data to BMS, which collects multiple variables to enable examination of health, functional and psychosocial outcomes in adults and children with moderate to severe burns (<https://burndata.washington.edu>).

The limited number of authors/institutional groups represented in the literature reveals a relative paucity of activity in contracture research, even in HICs. Characteristics of the 9 full papers are summarised in Table 2-3 and a detailed appraisal of each paper follows in 2.6.1.

Table 2-3: Characteristics of risk factor studies from HIC

Article	Country of Origin	Type of Study	Sample Population	Sample Size	Treatment Defined	Variables Measured	Follow up Period	Significant Risk Factors for Contracture
Kraemer et al. 1988	USA	Retrospective study over 5.5-year period	Paed + Adult patients requiring contracture release	53	Yes for 31 patients	Age, sex, race + burn size, location & depth	Not specified; based on time of contracture release	Being a child, greater burn size & depth, burn location (head/neck/axilla/hand)
Schneider et al. 2006	USA	Prospective over 9-year period	Adult	985	No but all treated at one centre	Gender, age at injury, ethnicity, length of stay (LOS) in ITU and in hospital, comorbidities, cause of burn, inhalation injury, neuropathy, heterotopic ossification, amputation, TBSA burned and grafted	Mean 22 days (hospital discharge)	Presence: Length of stay, TBSA grafted, TBSA burned Severity: amputation and inhalation injury risk factors for more severe contractures

Table 2-3: (continued)

Article	Country of Origin	Type of Study	Sample Population	Sample Size	Treatment Defined	Variables Measured	Follow up Period	Significant Risk Factors for Contracture
Gangemi et al. 2008	Italy	Prospective over 12-year period	Adult	703 (2440 burns)	Yes	Age, gender, TBSA, full thickness area, cause of burn, wound healing time, number of surgical interventions, date of first SSG and type of skin grafting (mesh)	Complete healing and maturation (max 29m)	* Younger age, female, TBSA (greater), full thickness TBSA (greater), anatomical location of burn (upper limb and neck), requirement for surgical procedures and number of procedures, time to wound healing and timing/type of excision/grafting
Kidd et al. 2013	Wales UK	Retrospective over 3-year period	Paediatric (<16y), requiring surgery for initial Rx	94	No but all had surgical Rx in acute phase	Age at injury, gender, mechanism of injury, type of surgery performed	12.7-14.6y median 13.6y	Young age at injury (< 5 years), higher TBSA, axillary burn
Hop et al. 2014	Netherlands	Retrospective multicentre, over 4-year period	Paediatric + adults referred to burn centre for initial Rx	1768	Yes, standardised protocols	Gender, age, aetiology, full thickness TBSA, total TBSA, no. of surgeries during acute phase	10 years	**Higher TBSA, flame burns, upper limb burns, number of surgeries during acute phase

*Outcomes defined in terms of pathological appearance of scar, not simply contracture

**Risk factors related to any reconstructive surgery, not just contractures

Table 2-3: (continued)

Article	Country of Origin	Type of Study	Sample Population	Sample Size	Treatment Defined	Variables Measured	Follow up Period	Significant Risk Factors for Contracture
Goverman et al. 2017a	USA	Retrospective, multicentre, over 10-year period	Paediatric (<18 y)	1031	No	Age, gender, ethnicity, hospital and ITU LOS, co-morbidities, cause of burn, inhalation injury, neuropathy, heterotopic ossification, amputation, TSBA burned and grafted	Mean 24.3 days (hospital discharge)	Presence: Greater age, ICU stay Severity: age, ICU LOS, amputation, black race Number of contractures: TBSA burned and grafted
Goverman et al. 2017b	USA	Retrospective, multicentre, over 10-year period	Adult	1065	No	Age, gender, ethnicity, hospital and ITU LOS, co-morbidities, cause of burn, inhalation injury, neuropathy, heterotopic ossification, amputation, TSBA burned and grafted	Mean 25 days (hospital discharge)	Presence and severity: Male sex, black/Hispanic ethnicity, pre-existing medical problems, TBSA burned, TBSA grafted, presence of neuropathy Number of contractures: Male sex, medical problems, flash-burn, neuropathy, TBSA burned and grafted

Table 2-3: (continued)

Article	Country of Origin	Type of Study	Sample Population	Sample Size	Treatment Defined	Variables Measured	Follow up Period	Significant Risk Factors for Contracture
Godleski et al. 2018	USA/Canada	Retrospective, multicentre, over 10 years	Adults with contractures	659	No	Anatomical location, burn size and LOS	Mean 31.9d (hospital discharge)	Contracture severity correlates with TBSA burned and LOS
Schouten et al. 2019	Netherlands	Prospective, multicentre, 12 months	Adult	173	Yes	Mainly burn data and ROM assessments	ROM measured up to 12m, total FU 24m	Operated burns (deep burns), burns over vs. adjacent to joint, anatomical location of burn and affected joint, TBSA burned, early stages of burn healing

2.6.1 Papers from HIC Settings

Kraemer et al (1988)

In 1988, Kraemer and colleagues reported factors contributing to contractures requiring surgical release as well as the results of surgical treatment in a sample of 53 adults and children over a period of 5.5 years. Patients were stratified according to location of acute treatment (main centre or referred from other hospitals), as a prophylactic acute treatment protocol had been introduced at the main centre to prevent contracture development. They noted that although burn size did not of itself affect contracture development, it did affect the number of contractures which occurred in a single patient. They observed an increased prevalence of contractures requiring surgical release in children compared with adults. They also found that certain joints more frequently required contracture release, namely head/neck, axilla and hand.

However, it was not clear how many joints were initially considered to be at risk, therefore the data on contracture incidence may simply refer to the incidence of burns in those areas. As the authors used a combination of visual, functional and range of movement (ROM) data gleaned retrospectively from notes to determine contracture presence, it is possible that some additional patients had contractures which were deemed too minor or inappropriate for surgery and were not included.

Schneider et al (2006)

In 2006, Schneider et al reported the results of a comprehensive prospective study of the development of contractures in 985 patients treated at a single centre. This was the first major study specifically focused on the identification of determinants for burn contracture formation and set a precedent for subsequent publications. Schneider et al. (2006) stated "there exists no

published prospective study on the incidence and severity of contractures in burn injury" (p.509); their study aimed to fill this gap.

The authors documented a range of variables in order to identify risk factors for contracture development at the shoulder, elbow, hip and knee joints. The variables were gender, age at injury, ethnicity, length of stay (LOS) in the Intensive Therapy Unit (ITU) and in hospital, co-morbidities, cause of burn, inhalation injury, neuropathy, heterotopic ossification, amputation, TBSA burned and TBSA grafted.

Contractures were well-defined, using goniometer measurement in multiple planes of movement; any deficiency in normal ROM in any plane was considered to be a contracture. No definition of a joint at risk was provided. It is unclear whether all major joints were included, or only those considered to be at risk of (or having developed) a contracture. Since the total yield of joints from 985 patients was 7880, and data were reported on 1591 joints, it is possible that only joints at risk with/without contracture were included in the analysis. Schneider et al. (2006) state in the results section "burn injuries that cross a major joint likely result in a greater risk of contracture development at that joint" (p.511) but data to demonstrate this finding are not reported.

This is only the second study to document contracture severity. Normal ROM at each joint was divided into thirds to represent a mild, moderate or severe contracture depending on how many thirds (or parts thereof) were affected by the loss. The study endpoint was limited to the time of discharge of the patient after acute burn admission (average 22 days). Since contractures may continue to develop for many months or years after a burn, this cannot be considered to be a complete evaluation, but the study did contribute detailed information on patients having standardised treatment in a single centre.

In this study, 381/985 patients (39%) developed at least one contracture of the joints studied, which is a high rate for a HIC regional burn centre with standardised state-of-the-art treatment. Shoulder flexion and abduction, knee flexion and elbow flexion were the most frequently identified contracture locations; shoulder and elbow accounted for 72% of all contractures. The authors highlighted that the predominance of upper limb contractures has implications for functional problems. Although not stated by the authors, these findings may also indicate that the risk of contracture development varies by joint location. Statistically significant predictors of contracture development (presence and number of contractures) were longer length of stay, higher TBSA burned and higher TBSA grafted. These factors were also related to the number and severity of contractures, with amputation and inhalation injury being additional risk factors for severity.

Schneider et al. (2006) stated, “this study underscores the importance of positioning and intensive therapy intervention in hospitalised burn patients” (p. 512), however this conclusion is only partially supported by the data and may reflect the authors’ opinions. Early physiotherapy interventions may be valuable in HICs, where other system and treatment risk factors are addressed to a high standard, but they may not be the most important factor in risk mitigation for burn contractures in LMICs.

Gangemi et al (2008)

Gangemi et al. (2008) reported analyses of standardised clinical records of 2440 burns in 703 adult patients attending a Burns outpatient clinic in Turin, Italy, over 12.3 years. Data were collected prospectively from the time of injury until full healing of burn and scar formation (maximum 29 months). Rigorous and frequent follow-up was maintained until full recovery and maturation of scarring. Demographic, burn and surgical treatment variables collected and

evaluated for each body area involved. Outcomes were defined in terms of the appearance of the scar, which was categorised as normal, hypertrophic with/without contracture, or contracture with/without atrophy. The clinical features used to define contracture were “skin coarctation or deformity” and reduced range of movement (neither of which were further defined) in addition to “subjective sensation of constriction”(Gangemi et al., 2008, p. 96) This is the only study to use this measure. It is not clear if the term ‘contracture’ was limited to joints or, (as seems more likely), was being used to include contracted hypertrophic scars elsewhere.

The results showed that significant individual predictors of contracture of a scar included TBSA (greater), full thickness TBSA (greater), anatomical location of burn, requirement for surgical procedures and number of procedures, time to wound healing and timing of excision/grafting (Table 2-3). From multivariate analysis, only gender (female), age (young), burn site (upper limb and neck had greatest risk), number of surgical procedures (higher) and type of skin graft (mesh) were useful contributors to the overall patient risk. However, since the last 2 factors can only be identified after complete burn healing, it is not possible to use this prognostic model at the outset of treatment.

This study cannot be directly used to identify factors which would definitely be significant risks in the development of joint contractures after burns, as the study population predominantly comprised patients with hypertrophic scarring rather than contractures. However, the study does add to the range of individual predictors for pathological scarring which is an intrinsic component of joint contracture.

A significant contribution of this study is the observation that pathologically contracted scars have a median latency of 27 days (range 10-55 days) and a

long healing time (up to 29 months). This emphasises the need for long follow-up in studies purporting to evaluate the prevalence of, or risk factors for, contracture.

Kidd et al (2013)

In 2013, Kidd and colleagues reported the outcomes in paediatric burn patients documented over a 3-year period on the Welsh National Burns Database. Patients included in the study had all undergone surgical treatment (grafting+/-flap) during the initial treatment phase. Mean follow-up was 5.1 years. Of the 94 patients included, only 17 (18%) developed contractures within 13 months of injury (mean 3.9 months), indicating that even deep burns requiring surgical input can heal without contracture. The authors noted that axillary burns were more likely to become contracted than other joints. The factors identified as risks for contracture were young age at burn (< 5 years), higher TBSA and anatomical location (upper limb, head/neck more at risk). However, how contracture was defined or measured and how joints at risk were defined was not stated. The study concluded that contracture development occurred within 18 months, leading to a change in their clinical follow up practice.

Hop et al (2014)

Hop and colleagues (2014) conducted a detailed 10-year follow-up on children and adults (n=1768) referred to 3 Dutch burn referral centres for initial treatment between 1998 and 2001. Patients were treated according to standardised protocols and the outcome measure was any need for reconstructive surgery during the follow-up period, including surgery for contractures and scarring. Although contractures were the most frequent indication for reconstructive surgery (72% of all surgeries), no details were given on contracture definition or severity. Multivariate regression analysis

identified upper limb burns, fire/flame burns, higher TBSA and the number of surgical interventions in the acute phase as independent predictors for reconstructive surgery. However, the data presented did not identify whether these risk factors were also valid for contracture development alone.

Goverman et al (2017a, 2017b)

In 2017, Goverman and colleagues published two virtually identical retrospective studies (one adult and one paediatric) based on the BMS dataset between 1994-2003 (Goverman et al., 2017a and 2017b). The methodology was similar to the single centre study by Schneider et al. (2006). Contractures were defined as any deficiency in active ROM (measured using a goniometer) in any plane of movement; contracture severity was categorised as mild/moderate/severe using the rule of thirds (Schneider et al., 2006). The presence, number and severity of contracture at all major joints, lumbar and thoracic spines were examined. The endpoint of the study was the time of hospital discharge (mean 24.3 days in children, mean 25 days in adults) which is very short.

No definition of a joint at risk of contracture was given. However, a later paper which used the same database (Godleski et al., 2018), indicated that only contracted joints were analysed. The overall incidence of contracture at discharge was 23% in children (237/1031 patients) and 33% in adults (620/1065 patients). The average number of contractures in affected patients was 3.32 for children and 3.38 for adults.

For children <18 y of age, increased contracture severity was directly correlated with age, ICU length of stay, amputation and black race (Table 2-4). TBSA burned and TBSA grafted were significant predictors for the number of contractures per patient but were not independent predictors of the presence

of a contracture. Shoulder and elbow were the most frequently contracted joints.

In adults, statistically significant risk factors for contracture development and severity were male sex, black or Hispanic ethnicity, pre-existing medical problems, TBSA burned, TBSA grafted, and the presence of neuropathy. Predictors of the number of contractures included male sex, medical problems, flash-burn, neuropathy, TBSA burned and grafted. In all cases, female gender appeared to be a protective factor. The most frequently affected joints were the shoulder and elbow, although when present, ankle contractures were more likely to be severe.

As both these papers represent large multicentre studies, it is possible that there were subtle differences between institutions with respect to acute treatment protocols, especially those designed to minimise contracture formation. In addition, within the timespan of the database, care patterns may have changed.

The large populations and detailed analyses in these papers have resulted in the identified predictive factors being widely accepted and quoted as risk factors for contracture development. However, the short follow-up periods mean that an unknown number of contractures may have developed (or improved) at a later stage. This highlights the need for an agreed and accepted definition of contracture, not only with respect to actual ROM measurement but also regarding timing of assessment.

Godleski et al (2018)

In 2018, Godleski and colleagues published a paper on the outcomes of 659 severely burned adult patients identified from the BMS (the same database used in studies by Goverman (2017a and 2017b). The focus of this study was

quantification of contracture with two measures not previously reported (absolute measurement of loss of ROM and percentage loss of movement) at 7 major joints (shoulder, elbow, wrist, hand, hip, knee and ankle). There is no stated definition of a joint at risk of contracture, but only joints that had a contracture were included (6228 joints).

The risk factors examined were only anatomical location, burn size and LOS. In common with earlier studies from the same group (Goverman et al., 2017a and 2017b; Schneider et al., 2006); the endpoint was initial discharge from hospital after acute treatment (mean LOS 31.9d +/- SD of 24.7d). This short follow-up is potentially flawed and may both under- or over-estimate the true incidence of contracture. Shoulders had the highest loss of movement. In the majority of joint motions, contracture severity significantly increased with larger burn size and longer length of stay, confirming previous studies.

Schouten et al. (2019)

The most recent HIC paper identified by the literature search in this category was published by Schouten et al. (2019) from the Netherlands. This was a rigorous prospective multicentre study with the explicit aim of identifying the prevalence and natural history of burn contractures. Unlike many previous studies, Schouten et al. (2019) gave a clear description of what they considered to be a contracture, namely “an impairment caused by replacement of skin with pathologic scar tissue of insufficient extensibility and length, resulting in a loss of motion or tissue alignment of an associated joint or anatomical structure” (p784). Contracture was defined as any loss of passive ROM and classified as present or absent. A joint at risk was clearly defined as a burn over the joint or adjacent to the joint; adjacent was defined as being at a maximum distance of 1/3 of the length of the adjoining body part/limb. This is one of only three papers which defined a joint at risk.

Consecutive patients admitted (n=173 with 548 joints) to any of the 3 participating Dutch Burn Centres with acute burns across or adjacent to one or more major joints (neck, shoulder, elbow, wrist, hip, knee and ankle) over a 12-month period were included. All patients had standardised therapy during acute and rehabilitation phases. Participants had passive ROM in multiple planes measured frequently for all major joints during their initial admission, at discharge and every 3 months for a year. Patients were analysed in two groups – skin grafted or not. The outcome was whether the joint had limited movement or not. Authors used the need for skin grafting as a proxy for a deep burn. Follow-up was maintained for 2 years to capture any later reconstructive surgery.

Of the 548 joints, 47% had a measurable limitation of ROM at 3 weeks, declining to 9.4% after 12 months, confirming a natural tendency (with appropriate care) for contractures to diminish. Burns which required surgical intervention in the acute stage (and can therefore be assumed to be deeper) had a greater contracture rate, both at discharge and at 12 months, than those not requiring surgery in the acute phase. After 12 months, the most frequently contracted joints were the shoulder, followed by the neck, elbow, wrist, ankle, knee and hip, whereas at the early acute-phase assessments, lower limb joints were more affected. Although not clearly stated by authors, these results may illustrate that the anatomical location of the joint involved may of itself be a risk factor with some joints being more prone to persistent reduction in ROM than others.

Joint limitation in the non-operated group was 36.6% at 3 weeks, with no joint limitations at 12 months. In the operated group, 58.6% of joints were limited at 3 weeks and 20.9% at 12 months. This difference illustrates the impact of burn depth and management on burn contracture presence and severity.

This pattern of decreasing contracture rates over time may not be the same in LMIC settings. Comprehensive follow-up systems which provide necessary care throughout the trajectory of a burn injury post-discharge may be largely responsible for the observed improvement, rather than the natural history of contracture development. If prolonged effective care is not available, as often occurs in LMICs (Ramakrishnan et al., 2004), then contractures may not improve, and could even worsen over time.

Additionally, this study confirmed that burns crossing joints had more impact on ROM than those adjacent to the joint; more severe burns (both in depth and TBSA burned) are likely to have greater loss of ROM, and for a longer period of time. In their setting, burns requiring grafting are more likely to require corrective surgery for contracture at a later stage. The number of reconstructed joints was less than the actual number of joints with limited ROM, suggesting that studies using reconstructive rates as a proxy outcome for contracture may underestimate the total number of burn contractures in the population.

Interestingly, the overall prevalence of contracture at discharge was 57.4%, which is higher than rates reported by the American studies reported to date which also measured ROM at hospital discharge (39% Schneider et al., 2006; 42% Kowalske et al., 2003; 33.2% Goverman et al., 2017a). This may be the result of inconsistencies in defining joints at risk and underlines the importance of a standardised definition.

Notably, Schouten et al stated: “as burn scar contractures are a common sequela of burns it would be expected that their prevalence and development had been extensively studied. However, the opposite is true...” (Schouten et al., 2019, p. 784). This statement supports the view that there is a surprisingly limited amount of robust literature on burn contractures, especially considering how common and problematic they may be.

2.6.2 HIC Abstracts and Letter

Kowalske et al. (2003)

In 2003, Kowalske presented a multicentre study of the incidence and distribution of contractures following burns in adults and children to the American Burn Association; the abstract was subsequently published in the conference proceedings (Kowalske et al., 2003). This study retrospectively analysed 2,559 patients from the BMS database to identify the incidence and location of contracted joints at the time of discharge from hospital. Goniometer measurements of ROM in multiple planes were used to determine the presence or absence of contractures, but the movement loss used to determine a contracture was not stated. Patients were stratified by age (<18y, 18-60y and >60y) and measurement techniques were standardised, but no data were given regarding treatment.

In common with other American publications, the endpoint for measurement was discharge from hospital, which is very early in the natural timeline for contracture development and maturation (Schouten et al., 2019). Contractures were more frequently observed at discharge in Hispanic children, adults of black race, patients with flame burns and those with high TBSA. The shoulder was the most frequently contracted joint but there were no data on the distribution of joints at risk, therefore true contracture incidence is difficult to assess. The anatomical distribution of contractures matched the anatomical distribution of body parts burned.

Richard et al. (2013, 2015)

In 2013, a letter from Richard and colleagues was published in response to a paper from the Netherlands on the impact of static splinting on contracture development (Schouten et al., 2012). The letter presented an analysis of data from 2 other papers on the effect of static splinting in contracture prevention

at the neck, axilla, elbow, wrist and knee (Bunchman et al., 1975, Huang et al., 1978). They demonstrated that while splinting reduced contracture rates, duration of splinting was also important; the greatest reduction in contracture rates were seen in patients who were splinted for >12m. This analysis demonstrates that no splinting or insufficient duration of splinting may be risks for contracture. The primary studies on which the letter was based (Bunchman et al., 1975; Huang et al., 1978) are described in section 2.8.

The same group of authors undertook a prospective multicentre study on the effect of post-burn rehabilitation on contracture formation, which was presented at the American Burn Association in 2015 (Richard et al., 2015). The authors studied 307 adult patients with small (<10%TBSA) or large (>10%TBSA) burns. Using goniometer measurements, patients were stratified according to the presence or absence of contractures; neither the definition of contracture nor the distribution of affected joints were detailed. In common with most US publications reviewed, the endpoint for assessment was hospital discharge. The only factor which was significantly associated with contracture incidence was duration of rehabilitation therapy, expressed per Cutaneous Functioning Unit (CFU). Patients without contractures had almost twice the duration of rehabilitation therapy as those with contractures, regardless of burn size. This supports the concept that rehabilitation measures, if implemented early enough and for sufficient time, may reduce the risk of contracture formation.

2.6.3 Summary of Risk Factor Study Publications from HICs

The risk factors identified from these HIC studies are summarised and categorised in Table 2-4, which provides the foundation of a potential framework for categorising risk factors for contracture in future.

Table 2-4: Statistically significant risk factors identified from HIC papers

Category of Risk Factor	Significant Risk Factors for Contracture	No. of Papers	Author(s)
Demographic	Male gender	1	Goverman et al. 2017b
	Female gender – risk	1	Gangemi et al. 2008
	Female gender – protective	1	Goverman et al. 2017b
	Age at burn – children	3	Kraemer et al. 1988; Kidd et al. 2013; Goverman et al. 2017b
	Age at burn – younger adult	1	Gangemi et al. 2008
	Older age	1	Goverman et al. 2017a
Burn Factors	Ethnicity – black/Hispanic	1	Goverman et al. 2017a Goverman et al. 2017b
	Aetiology – flame/fire	2	Hop et al. 2014; Goverman et al. (2017b)
	TBSA burned	9	Kraemer et al. 1988; Kidd et al. 2013; Hop et al. 2014; Schneider et al. 2006; Gangemi et al. 2008; Goverman et al. 2017a and b; Godleski et al. 2018; Schouten et al. 2019
	Depth of burn	2	Kraemer et al. 1988; Gangemi et al. 2008; Schouten et al. 2019
	Anatomical location of burn	5	Kraemer et al. 1988; Gangemi et al. 2008; Kidd et al. 2013; Hop et al. 2014; Schouten et al. 2019
	Amputation*	1	Schneider et al. 2006; Goverman et al. 2017a
Medical Factors	Inhalation injury*	1	Schneider et al. 2006
	Pre-existing medical problems	1	Goverman et al. 2017b
	Neuropathy	1	Goverman et al. 2017b
Treatment Factors	ICU length of stay*	1	Goverman et al. 2017a
	TBSA grafted	4	Schneider et al. 2006, Goverman et al. 2017a,b; Schouten et al. 2019
	Type of graft	1	Gangemi et al. 2008
	Time to wound healing	1	Gangemi et al. 2008
	Need/no. of surgical procedures	2	Hop et al. 2014; Gangemi et al. 2008;
	Length of stay	2	Schneider et al. 2006; Godleski et al. 2018

2.6.4 LMIC papers Identifying Statistically Significant Risk Factors

Only 3 risk factor studies identified by the literature search were from LMICs, 2 from Ghana and 1 from Nigeria. One of the Ghanaian papers had shared HIC/LMIC authorship.

This demonstrates a lack of reported higher levels of evidence-based knowledge about burn outcomes in LMICs. All papers from LMICs are authored by doctors, which is admirable given that the environments they face are highly challenging both in terms of clinical demand and research capacity.

Forjuoh et al. (1996)

Forjuoh et al. (1995) reported a survey of children ≤ 5 years of age in the Ashanti region of Ghana. Their initial report examined the incidence, epidemiology and prevention of burns in this group. A follow-up paper based on the survey population aimed to determine the prevalence and risk factors for physical impairments and disabilities (including contractures) within the group (Forjuoh et al., 1996).

The initial survey involved a multi-site, cluster sampling of 5,000 households in 50 census areas of the region. Children ≤ 5 years of age were screened for scars or any other residual evidence of childhood burns. Of 15,742 children identified, 955 had evidence of previous burns (6.1%). The mothers of all 955 children were invited to participate in the study, 630 of whom were ultimately interviewed; the reasons given for those not interviewed were absence, inaccessibility or relocation. It is not known whether the distribution of burn severity +/- contracture incidence was the same in the children whose mothers were not interviewed.

Semi-structured interviews were conducted by trained medical students. Variables documented were age at burn, level of maternal education,

residential location, first aid given, whether there was healthcare contact or not, location of burns, depth of burn, level of healthcare treatment accessed, burn TBSA and depth, healing time, and number of days of limitation. Impairment was defined as any loss or abnormality of an anatomical structure or function at the end of initial burn treatment and physical disability was defined as any limitation in performing an age-appropriate activity as a result of a burn impairment. No measurements of the extent of impairment/disability were given; only functional tasks were described. This is the only LMIC study included in this review which attempted to define outcomes related to contracture. However, the definitions used were broader than contracture alone; 79% of children had keloids and 6% had contractures or amputations.

Of the 630 children with previous burns, 113 (17.4%) had evidence of physical impairment, of whom 7 (6%) had contractures +/- amputation. The authors reported 5 children who had a disability as a result of the impairment but did not state whether these were in the contracture/amputation group. Due to these small numbers, the analysis of potential risk factors was undertaken on the whole group, including children without contractures.

Factors which were found to be statistically significantly associated with physical impairment after burns were:

- age of child at burn injury
- burn of head/neck and trunk/back
- depth of burn (described as: only redness of skin/blisters without skin removal/ involved skin removal/deeper)
- number of days required to heal (described by category <14 days, 15-30 days, >30 days)
- infection of burn wound (no data presented)

- contact with health facility (no contact = greater risk)
- level of facility visited (lower level = greater risk)
- number of days of limitation (not defined)
- lack of maternal education
- lack of first aid post burn

The authors used multivariate analyses to identify potentially significant cut-off points for some risk factors. They found that risk of impairment was highest in burns which took >30 days to heal and in burns to the head/neck. The risk of impairment appeared to diminish after 12 months of age up to 35 months but increased thereafter; those aged 4-5 years had the highest risk.

Although this study did not specifically examine risk factors for contracture development, it offers some important insights into differences in LMIC post-burn follow-up, assessment and study compared to HIC settings. The authors included factors unrelated to the burn injury or treatment in their evaluation of potential risks, including residence location, availability of first aid or any health facility contact, and level of maternal education. The impact of such factors on the long-term outcome of burns is not considered in HIC literature.

The authors also categorised identified risks as being burn-related factors (e.g., depth of burn, infection, duration of healing), manipulatable (or changeable) factors (e.g., administration of first aid, maternal education) and nonmanipulable (unchangeable) factors (e.g., location of burn, age at burn). This may offer a further refinement of the categorisation of risk factors illustrated above in Table 2-4.

Fatusi et al. (2006)

The second LMIC paper identified from the literature search came from a specialist burn referral unit in south-west Nigeria (Fatusi et al., 2006). A

retrospective review of 139 patients with moderate-severe burns admitted over a 6-year period was conducted from a pre-existing register. This is the first LMIC paper to outline the standard of care received by patients, which consisted only of debridement, daily dressings, antibiotics and pain control.

The authors were specifically interested in any differences in outcome (contracture, wound sepsis, inhalation injury and death) between patients with or without facial burns. There was no significant difference found in rates of wound infection, contracture or inhalation injury between patients with or without facial burns. There was also no significant difference in any of the sociodemographic or burn-related variables studies between the two patient groups; mortality rates were also similar.

No definition or measurement of contracture was made. Unfortunately, the authors did not provide any data on the variables studied with respect to complications other than death; it is therefore not possible to know if any of the variables studied were significant prognostic indicators or risk factors for contracture. Consequently, although this paper met the criteria for inclusion in the literature review, it did not add to the search for risk factors for contracture.

Agbenorku (2013)

The last of the 3 LMIC papers included also came from Ghana (Agbenorku, 2013). This was a single centre study from a teaching hospital with a specialised burns referral unit; data were collected through patient examination and interview. One of the aims of the study was to identify potential risk factors for disabilities caused by burns.

The study was undertaken over one year and included patients who presented for follow-up after discharge from hospital, had some form of functional

disability and who consented to be interviewed. This was a self-selected population and did not include all burns survivors; routine follow-up of all patients is not usual in LMIC settings. The total number of admitted patients over the 12-month period was not reported, therefore the follow-up rate is unknown.

Data were collected through patient interviews using a specifically designed and pre-tested questionnaire; details of the personnel administering the questionnaire were not provided nor were the nature of the questions. The questionnaire was divided into 4 sections:

- i) demographic, including age, gender, occupation, aetiology of burn, depth of burn, TBSA
- ii) status of disability, including anatomical position affected, time lag between injury and disability
- iii) social burden caused by disability, namely the effect of disability on social interaction and social belief (not clearly defined)
- iv) economic burden caused by disability, compensation for injury, and social security or dependence of other people for survival (not clearly defined).

Unfortunately, all disabilities (including hypertrophic/keloid scarring, contracture, amputation and disfigurement) were grouped together for the purposes of analysis; it was not possible to identify the impact of any variables on contracture alone. There were 43% scar contractures and 38% disfigurements. This is the only LMIC publication in this section to report data on location of the contracture and whether patients had more than one contracture. Most frequently affected was the axilla (11/30). Risk factors were analysed by person not by joint.

Seventy patients, aged from 8 months -78 years were included: there was wide variation in the timing of assessment post-burn (1-105 weeks) therefore patients were at very different stages on the timeline of scar maturation. Multiple regression analysis showed that age <10 years, burn depth and anatomical location in axilla or head/neck were statistically significant associations with disabilities of all types; it was not possible to determine the impact of any of the variables on contracture formation specifically. Of note, unlike most HIC studies, TBSA (which ranged in the study population from 9%-75%) was not statistically significant.

All patients had some socioeconomic and psychological burden as a result of their disability; in many cases this led to an emotional or physical inability to return to work, with a resulting negative impact on economic, personal or family status. This is the only paper which considers the impact of patient disability on caregivers. Factors that were statistically significant were the impact on carer's time and financial limitations. Participants with a supportive nuclear family were found to have statistically significantly less disability and those with disability had a statistically significantly greater amount of mockery/stigmatisation from their community. This reinforces the need for more research into factors predisposing to adverse or improved outcomes after burns in LMICs.

2.6.4.1 Summary of LMIC papers

A summary of the key characteristics of the papers from LMICs is shown in Table 2-5 and their findings are summarised in Table 2-6. None of these papers provided any strong evidence for potential or actual risk factors for contracture development. Additionally, none of the papers defined the duration between burn injury and assessment. However, all introduced the

concept that socioeconomic factors play a part in adverse outcomes in LMIC and that the impacts of such disabilities or deformities may be severe.

Comparison of the risk factors for contracture identified by HIC publications (Table 2-4) with those identified as risk factors for impairment or disability in LMIC papers (Table 2-6) shows that although there are some areas of overlap (young age, TBSA burned, depth of burn, anatomical location of burn and duration to healing), socioeconomic factors are not even mentioned as potential risks in the HIC papers.

Additionally, the concept that some potential risk factors for adverse outcomes may be modifiable, while some are not, is important.

Table 2-5: Characteristics of risk factor study papers from LMICs

Article	Country of origin	Type of Study	Sample Population	Sample Size	Treatment Defined	Follow-up time	Adverse Outcomes Studied
Forjuoh et al. 1996	Ghana	Retrospective, multisite cluster sampling	Paediatric 0-5 years	650 burns, 113 children with post-burn impairment	No	Not stated but age ranged from 1-59 months	Any impairment, including scarring, keloids, contracture and amputation
Fatusi et al. 2006	Nigeria	Retrospective, single site	Mixed adult/child patients	139	Overview of standardised treatment protocol provided	Not stated: at hospital discharge	Wound infection, contracture, inhalation injury, death
Agbenorku 2013	Ghana	Single centre, predominantly descriptive	Adults and children, selected patients with disability	70	All treated at one centre, standardised protocol	1-105 weeks	Disability: scar +/- contracture +/- disfigurement

Table 2-6: Findings in risk factor studies from LMICs

Article	Variables Measured	Significant Risk Factors for Adverse Outcomes
Forjuoh et al. 1996	Age at time of burn, level of maternal education, residential location, first aid, whether there was healthcare contact or not, location of burns, depth of burn, level of healthcare treatment accessed, burn TBSA and depth, healing time, number of days of limitation (not defined)	Nonspecific to contracture but risk of impairment associated with: Age of child at burn injury TBSA (no data presented) Burn of head/neck and trunk/back Depth-of burn - deeper Longer number of days required to heal Infection of burn wound (no definition or data presented) Contact with health facility (no contact) Level of facility visited (lower level) Number of days of limitation Lack of maternal education Lack of first aid
Fatusi et al. 2006	Age, gender, cause of burn, depth of burn, time to presentation, depth and causes of burns, incidence of complications	Not stated: variables only examined for difference between 2 groups (facial burn involvement or not), both groups had same contracture prevalence (9%)
Agbenorku, 2013	Age, gender, occupation, aetiology of burn, depth of burn, TBSA, location of burn functional limitation, socioeconomic impact of disability	Not specific to contracture but risk of disabilities associated with age <10 years, 3 rd degree burn depth, anatomical location (axilla or head/neck), social mockery, impact on carers finances and time Protective – supportive nuclear family

2.7 DESCRIPTIVE STUDIES

Thirteen publications identified by the literature review were classified as descriptive (observational studies of differing patient cohorts) and did not include statistical analyses of any potential risk factors in contracture development. As these papers documented a range of variables which may be of importance in determining patient outcome, they are reviewed in detail. Five descriptive studies were from HIC settings and 8 were from LMICs.

A single descriptive case report of 2 patients from a LMIC setting was also included in this section, recognising that case reports are lower in the hierarchy of evidence than cohort studies (Guyatt et al., 1995).

2.7.1 Descriptive Studies from HIC

The five HIC descriptive studies are detailed below in chronological order of publication.

Dobbs & Curreri (1972)

This is the earliest descriptive paper identified by the literature search and has a large study population (n=681). The paper was included in the systematic review by Oosterwijk et al. (2017). All patients were treated in a single US Army institution and had the same standardised treatment including a well-described intensive physiotherapy regime from the day of admission, including hydrotherapy, anti-contracture positioning, splinting, exercise, and avoidance of immobilisation.

The main outcome of interest was contracture, defined as any loss of movement at affected joints, which was assessed by physiotherapists (no measurement data is reported) at the time of discharge from acute care (average LOS not reported) and 30 days later. Measurements were taken at both time-points, but reported only for one, which time-point was used is not

stated. This was the first paper to define a joint at risk of contracture and consider this in the inclusion of joints. The joint was included "if the surface on or across the joint was burned" (Dobbs & Curreri, 1977, p. 242). However, Dobbs & Curreri later stated that ten patients were included who did not have a burn over or across the joint because contracture may result "whether or not the joint surface is burned, due either to proximity of burn to the joint or the immobilisation associated with the treatment" (p. 242).

Overall, 188/681 (28%) patients developed contractures and 523/3312 (15%) joints at risk became contracted. These rates are lower than those reported in later American studies reviewed, which is surprising given the improvements in care which have occurred since 1972. Most participants in the Dobbs & Curreri (1977) study were active serving military personnel who may be much fitter and more adherent to care than the average burn population. The clear definition of contracture and joints at risk may have contributed to the observed lower contracture rate.

The variables examined were TBSA, depth of burn and joint location. This is the first paper in which severity of contracture was also determined; three categories of severity were recognised - acceptable (50% or more of normal movement), functional (approximately 50% of movement) and severe (less than 50% of movement and reconstructive surgery is required to improve function). These categories would not be applicable today, as 50% loss of movement would normally be considered unacceptable. However, most descriptive statistics in the article relate to the presence or absence of limited movement rather than its severity.

The authors emphasised the importance of initiating physiotherapy treatment rapidly and demonstrated, through a descriptive case study and photograph,

an unexpectedly adverse outcome in one case of second degree burns in which physiotherapy was delayed by >2 weeks.

The study concluded that joints at risk with <2nd degree burns and even those with grafted full thickness burns <40% TBSA should not develop contractures if there were no complications and intensive physiotherapy was instituted promptly. Of the 523 joints with loss of movement, 509 had a burn over the joint, suggesting a relationship between burns over joints and subsequent loss of ROM. Severe contractures were found in 27% of joints; 92% of severe contractures were in joints with a third-degree burn. However, 79% of joints with any limitation had <third-degree burns.

In terms of risk factors, greater TBSA and greater depth of burn increased the likelihood of a severe contracture and full thickness burns involving subcutaneous tissue (especially joints and tendons) were most likely to result in contracture. The shoulder and hand had the highest incidence of contracture (19%), but the most severe contractures were seen in the hand and neck.

Pegg et al. (1979)

This paper explores the epidemiology and selected outcomes of 411 burn patients admitted to the specialist burn unit in Brisbane over a period of 5.5 years. The paper was included in this review because contracture was included as an outcome of interest. The prevalence of burn contractures reported was 7.8%, which is lower than in later studies. However, there was no definition of contracture or how severity of contracture was determined, no measurement methodology was stated, and the time of contracture diagnosis was not reported. No data were presented on anatomical locations of the contractures. The study used discharge from acute care as the end point; presumably the reported contractures were documented somewhere before

discharge. Average length of stay was 22.9 days which is early in the contracture maturation timeline (Schouten et al., 2019).

The study included more males (293) than females (118), however 14.4% of females developed a contracture but only 5.1% of males. Gender is the only variable for which data are presented in relation to the prevalence of contracture. The authors concluded that there did not appear to be a relationship between age and contracture incidence by gender, that contracture formation was more common in patients who sustained higher TBSA burns of full thickness and that neck contractures were more common in females; all three statements were made without the presentation of supporting data.

Gorga et al. (1999)

In 1999, Gorga and colleagues studied 51 children <6 years old (average 27 months) at 1-, 6- and 12-months post-burn, to investigate physical, functional and developmental outcomes after discharge from a specialised burn unit in New York. Contracture was one factor used to measure physical outcome. A joint was defined as having limited ROM if it did not have full ROM as defined by the American Academy of Orthopaedics for passive ROM assessment. Gorga et al., (1999) that “measurement was taken of the burned area whether burn crossed a joint or not” (p. 172). Burn location was reported by head/neck, upper limb, lower limb or hand, but it is unclear if all joints measured were at risk of contracture or not. All patients had specialised burn care, with rehabilitation during admission and as needed after discharge. As seen in other studies in this literature review, retention of participants throughout the study period was poor (51/248); reasons for this were not provided.

The contracture outcomes were difficult to determine from the data presented. It appears that less than 5% of patients had any loss of movement at any of the

follow-up points in any of the areas assessed (head/neck, upper limb, lower limb or hand). Patients with burns to the head/neck and upper limb had 100% movement at 1 month and maintained this throughout. Those with hand burns had 100% of movement at 1 month, which reduced to 97%, then to 95% at subsequent measurements. Lower limb burns had 87% FROM at 1 month; full movement was recovered by the 6th and 12th months. These outcomes were reported for the whole group, and not related to individual characteristics or variables. No measures of contracture severity were reported.

However, average TBSA% was relatively small (6%), and 50% of all burns healed within 21 days, therefore scarring would not be expected. Burns that failed to heal within 21 days were grafted, which would also reduce scarring. Since the group had relatively low scores (range 3.6-7.4) on a scar assessment scale (minimum possible score 0 (no scarring), maximum 27 (severe scarring)), it is evident that the amount of scarring was small, which may be why fewer joints were contracted. The results may also indicate that the specialised burn unit from which participants were discharged had delivered effective burn care.

The findings highlight the problem of loss of follow-up even in HIC studies and also how size and location of the burn with regard to joints is likely to have a considerable impact on prevalence of contractures.

Other outcomes used in this study to assess the social and developmental features of the study population indicate that most parents of the children lived on public assistance (66%) and only had high school education; 48% of children were from what the author described as 'suspect home environments' (Gorga et al., 1999, p.175) and had some developmental concerns such as language development. Despite these socio-economic disadvantages, the physical outcomes were very favourable.

Richard et al. (2017) and Richard & Santos-Lozada (2017)

The first paper published by Richard et al. (2017) utilised the same study population (n=307) from the same database as their subsequent publication later the same year Richard & Santos-Lozada, 2017. The paper by Richard & Santos-Lozada (2017) introduced the ACT (Acuity-Contractures-Time) database, to which 13 burn centres contributed. The aim of the ACT database was to determine if there was an association between rehabilitation input and contracture. Richard & Santos-Lozada (2017) provided descriptive statistics for all 43 variables collected and reported on these for all 307 patients. This paper was useful to improve understanding of the methodology and variables reported in Richard et al. (2017). However, as no connection was made between the descriptors and outcomes (including contracture), focus here is on the study by Richard et al. (2017). These two papers by Richard are the only papers within this descriptive category which explicitly state that the descriptors were selected due to anticipated impact on contracture formation. Other than this statement, no further rationale is provided for the selection of the 43 variables.

Richard et al. (2017) analysed data from the ACT database to report on the selected variables in relation to patients who did not develop a contracture. This is the only paper identified by the literature search which focused on no contracture as the outcome, rather than presence or severity of contracture. “No contracture” was defined as full passive range of movement of the included joint. Normal ranges of movement were stated but no source was referenced. Standard deviations were reported for every joint measurement. This is also one of a few (n=3) studies to consider whether the joint measured for contracture was likely to be at risk of contracture or not. The method used to identify joints at risk utilised cutaneous functional units (CFU); joints were only included as being at risk if there was a burn within the relevant CFU

(n=1585). Cutaneous functional units (CFUs) are “fields of skin that functionally contribute to range of motion (ROM) at an associated joint” (Parry et al., 2017, p.106).

All major joints, plus the hand and jaw (mouth-opening) were included. As in most American studies, the time of outcome measurement was discharge from acute care; median LOS was 13 days (IQR 9.50-17.50) with a mean of 15.3 days (SD 10.3), which is very early in the burn healing timeline. Range of movement was the only outcome utilised in this study.

Only 18% of the population did not have a contracture, suggesting a very high prevalence of contracture (82%) despite specialised burn care. However, because measurement was at such an early stage of healing, factors other than a burn contracture may have contributed to the loss of movement, including dressings, oedema, and pain, which are all potential confounders to the capture of a true contracture.

Eleven factors were reported to be characteristics of the 56/307 patients who did not develop a contracture (Table 2-7). Only descriptive statistics were given; therefore, it is not certain how the eleven factors were identified. It is possible to speculate that the opposite characteristics could be risk factors for contracture. The characteristics of patients without contracture and the suggested converse potential risk factors are shown in Table 2-7 below. It should be noted that although definitions are given for variables, no cut-off points were reported and variables such as high TBSA or limited skin graft were undefined. Some descriptors were subjective, such as pain tolerance (rated as poor, good, excellent) or rehabilitation tolerance (excellent, good, fair, poor). Uncomplicated hospital stay was undefined.

Table 2-7: Features of patients without contracture and converse potential risk factors

Characteristics of Patients with NO Contracture	Converse Potential Risk Factors for Contracture
Small total burn size	High TBSA
Limited skin grafted area	High TBSA grafted
Educated	Uneducated
Inconsequential associated co-morbidity	Significant co-morbidity
Low incidence of psycho-social problems	Significant psychosocial problems
Uncomplicated hospital course	Complicated hospital course
Adequate hospitalization stay	Inadequate hospital stay
Sufficient daily rehabilitation time	Insufficient daily rehabilitation time
High ratio of rehabilitation time to hospital days	Low ratio of rehabilitation time to hospital stay
High pain tolerance	Poor or low pain tolerance
High compliance with rehabilitation	Poor compliance with rehabilitation

2.7.1.1 Summary of HIC descriptive papers

The 4 HIC descriptive papers reviewed (excluding Richard & Santos-Lozada 2017) generated a total of 11 potential risk factors for contracture development after burns. These are included in the overall summary shown in Tables 2-9 to 2-11 at the end of this section.

2.7.2 Descriptive Studies from LMICs

It is recognised that descriptive studies cannot reliably identify statistically evidence-based risk factors, particularly when it is not certain (and often unlikely) that the study population is fully representative of the whole or wider burns population. None of the LMIC papers referenced in this section were included in the systematic review which identified prevalence and determinants of burn contracture formation (Oosterwijk et al., 2017). However, these papers have been included in this literature review for the following reasons:

- i) to enable the inclusion and evaluation of a greater number of potential risk factors from LMIC settings

- ii) all the papers in this section were written by medical professionals (often surgeons) with a special interest in burns; the views presented will likely represent the clinical experiences of these healthcare professionals in the context of interest (i.e., LMIC) and are thus of value to this thesis
- iii) Related to ii) above, it could be speculated that if the outcomes of interest following burn injury/care include contracture, then clinical authors would be more likely to select measurable variables which they believe from their experience are likely to impact the outcome. Although these are subjective opinions, they may give some clues or insight into the nature of potential risk factors for burn contracture in LMIC settings.

Nine descriptive publications were found from LMICs, including 8 descriptive studies and one case report. The single case report describing 2 patients from Zimbabwe with 'gross deformity' following burns (Muguti & Mhaka, 1994) is not included in the tables that follow, but key points from the report are included at the end of this section.

2.7.2.1 Summary of general features of LMIC descriptive studies

A summary of the main features of the 8 descriptive papers from LMIC settings is shown in Table 2-8. Five papers reported retrospective studies and 3 were prospective. These 8 descriptive studies documented a range of characteristics and outcomes in various populations of burn patients over study periods of 7 months to 10 years. In each study, contracture was either the only outcome of interest, or one of several outcomes recorded.

Table 2-8: Key features of 8 LMIC descriptive studies

Reference	Location	Population	Type of study	Duration	Main Outcomes Documented
Sowemimo, 1983	Nigeria	89 acute burns; adults & children	Retrospective from medical records	8 years	Mortality and morbidity including contracture
Muguti & Fleming, 1992	Zimbabwe	53 adults & children seeking reconstruction	Retrospective from hospital records	3 years	Contractures
Ramakrishnan et al. 2004	India	459 children with acute burns	Retrospective, data source not stated, possibly medical records	10 years	Contractures, hypertrophic scars, other morbidity, rehabilitation need
Aramani et al. 2010	India	100 acute burns; adults & children	Prospective cross-sectional	12 months	Residual disability (scarring +/- contracture), death
Kim et al. 2012	India	31 adults & children at reconstructive surgical camp	Retrospective	1 week	At least one contracture requiring surgery
Saaiq et al. 2012	Pakistan	213 adults & children with contractures	Prospective observational	4 years	Surgical outcomes of contracture release
Ringo & Chilonga, 2014	Tanzania	41 acute burns; adults & children	Prospective	7 months	LOS, sepsis, contracture, death
Agbenorku et al. 2015	Ghana	17 chemical burns; adults & children	Retrospective from ICU register	4 years	Contracture, blindness, scarring

2.7.2.2 Study populations of LMIC descriptive studies

Study population sample sizes ranged from 17-459. Seven of the 8 reports included both paediatric and adult patients; one study focused on paediatric patients only (Ramakrishnan, et al., 2004). This observation illustrates a significant difference between HIC and LMIC literature, which reflects the patterns of clinical care in these different settings. Due to limited resources in LMIC, adults and children are often treated in the same units and often in the same wards, whereas in HICs children are usually treated separately in specialised paediatric facilities; this is often reflected in a separation of analyses of paediatric and adult populations for research purposes in HIC. The mix of adults and paediatrics may also affect the risk factor profile, as the risks for adults and children may be different.

Three papers reported only on patients who had developed at least one contracture and presented to a surgical camp (Kim et al., 2012), or hospital (Muguti & Fleming, 1992; Saaiq et al., 2012) to seek reconstructive surgery. The remaining 5 papers reported on patients with acute burn injuries: one of these focused only on acute patients with chemical burns (Agbenorku et al., 2015).

Unlike HIC studies, which can often utilise single or multi-centre, regional or even national databases and have accurate medical notes for data collection, at least 50% of LMIC studies relied wholly or partly on data extraction directly from the patients or their carers. This introduces the possibility of data inaccuracy resulting from poor communication between investigator and patient/carer, poor understanding by patients/carers and inaccurate patient/carer recall of events. One LMIC study used data from a local (ICU) burn database (Agbenorku et al., 2015) and 3 retrospective studies collected data from medical notes, the quality of which is uncertain (Muguti & Fleming, 1992; Ramakrishnan et al., 2004; Sowemimo, 1983).

2.7.2.3 Variables documented

A wide range of variables were documented in these 8 LMIC papers. Only one paper attempted to associate any of the variables collected with contracture outcome (Aramani et al., 2010); the remainder did not relate any specific patient characteristics to contracture.

It is therefore not possible to report with confidence any definite risk factors for burn contracture from the LMIC papers included in this section. Nevertheless, it is useful to note the range of variables collected, as they may provide some insight into the factors that are presumed to be relevant to contracture formation in that setting. The LMIC papers not only considered patient demographics but also socioeconomic factors; this is a recurring theme in LMIC studies. Additionally, the LMIC papers note that the use of, timing and duration of treatment modalities (ranging from resuscitation and fluid management through to dressings, surgery, skin grafts and rehabilitative therapies) are believed to have an impact on outcomes, including contracture formation. This emphasises how complex the risk factors for contracture may be in LMIC settings; not only do they include actual injury factors, but also patients' backgrounds, socioeconomic status, and the degree of sophistication and timing of treatment modalities available. The differences between HIC and LMIC settings in these respects are crucial and are highlighted further below.

2.7.2.4 General quality of LMIC papers

HIC papers were more detailed than the LMIC papers and were of higher quality. The overall quality of the papers reviewed in this section was poor:

- a) Inclusion criteria for many studies were absent or vague
- b) The stated aims of the study were often not satisfied

- c) Only 2 studies documented any ethical or institutional approval; in these settings ethical approval may not be needed for these types of studies
- d) The data collection process was often lacking in detail or not described at all
- e) The analysis of data was often poorly described, e.g., "After feeding the data into the computer, analysis was started." (Ramakrishnan et al., 2004, p. 146)
- f) Article titles often did not accurately reflect the content of the article
- g) There were reports of data being collected, but those data were not presented in the results
- h) Missing data were rarely accounted for in interpretation of data or in discussion of limitations
- i) There was a lack of definition of terms used for both variables and outcomes
- j) Results and conclusions often included clinical opinion rather than being supported by the data in the study; occasionally conclusions were offered without any prior reference or supporting data
- k) The limitations of the studies were usually not mentioned at all, and no limitations of methods were reported.

2.7.3 Summary of Variables and Outcomes in Descriptive Papers

The papers reviewed in this section demonstrate some important differences between HIC and LMIC publications in the nature of variables collected, and outcomes considered.

Tables 2-9 to 2-11 at the end of this section present a comprehensive list of the patient characteristics reported in both HIC and LMIC papers; the collected variables have been organised into categories utilised earlier in this chapter for the reporting of risk factors. The purposes of these tables are a) to illustrate the wide range of potentially relevant factors which may be associated with contracture outcome, b) to show the difference in focus between HIC and LMIC authors and c) to inform the present study about all factors which should be considered in planning primary research in a LMIC setting.

2.7.3.1 Patient characteristics

Patient characteristics shown in Table 2-9 include the collected variables categorised as demographic and socioeconomic factors.

Of all categories, there is most consistency between HIC and LMIC variables collected in the demographic category. All but one paper (Dobbs & Curreri, 1972) collected data on the gender and age of the patient. Ethnicity was not noted in any LMIC papers; the assumption is that there is less or no diversity of ethnic group in these studies than in the HIC studies. Time since burn was only documented in 2/4 HIC papers and 3/8 LMIC studies; this is relevant when considering the likely timeline for contracture development. As highlighted previously, most HIC papers used hospital discharge as an endpoint, which is early in the natural history of contracture formation; Dobbs & Curreri (1972) followed patients for 30 days post discharge.

More interest is expressed in socioeconomic factors by LMIC papers than HIC. Richard et al. (2017) and Gorga et al. (1999) considered the educational level of patients/carers in HIC publications; in contrast, 5/8 LMIC papers documented the educational history of the patient. This suggests that education may be believed to be an important contributory factor to burn outcomes in LMICs, perhaps in relation to understanding and adherence to treatment or access to effective care, or as an indicator of socioeconomic status. No data on residence location was documented by HIC papers but 2/8 LMIC papers recorded whether the patient lived in a rural or urban setting. This suggests that LMIC researchers are more aware of difficulties faced by rural populations in readily accessing medical care; in HIC, ready access to immediate and appropriate healthcare seems largely taken for granted by researchers. Conversely, only 1/8 LMIC papers reported on the presence of any pre-existing co-morbidities, but HIC papers detailed these extensively. This may be due to greater sophistication of medical care and diagnosis and the availability of accurate medical records in HIC settings.

2.7.3.2 Burn-related factors

Data on patients' medical characteristics and burn-related factors were extensively documented in both LMIC and HIC settings (Table 2-10). However, the amount of detail recorded in HIC papers was much greater, and definitions were much clearer. The cause of the burn was documented in both HIC and LMIC papers, but more attention was given to the mechanism of injury in LMIC publications. Of the HIC papers, only Pegg et al. (1978) gave specific details on mechanism of injury. This seems to indicate a greater focus on public health issues and potential preventative strategies in LMIC settings; several LMIC authors emphasised the need for prevention in their conclusions.

2.7.3.3 Treatment factors

Treatment factors were far more extensively collected in the HIC studies and are summarised in Table 2-11. Nineteen of the 33 treatment factors documented overall were only mentioned in HIC studies. Factors that were only reported in LMIC studies were first aid given, any treatment vs no treatment, place of initial burn care, nature of initial treatment, time to treatment at hospital, time to skin graft and overall wound healing time. LMIC interest in these factors is indicative of the considerable differences in healthcare availability and systems between HICs and LMICs.

In HIC settings, rapid availability of informed first aid and standardised initial burn care in a medical facility is largely taken for granted; consequently, researchers may see no need to document these variables as potential influences on outcome. There is little need in HIC studies to include 'no treatment' as a potential risk variable, as it would be expected that all patients with a burn injury would access some level of healthcare treatment, which would be delivered without delay. Furthermore, burn care in the HIC setting is more standardised and often driven by specialist protocols, even in non-specialist institutions, therefore the place of initial burn care may be less relevant to outcome.

In LMIC contexts, where standardised treatment protocols are much less common, whether the patient is treated initially at a specialist centre or in local primary care could have a strong influence on outcome. Only one LMIC paper (Sowemimo, 1983) reported LOS (mean 37 days). This is still not a long period of time but is greater than all reports of mean LOS in the HIC papers.

Documentation of care in HIC medical records is also much more detailed and accurate (possibly for medico-legal reasons as well as resource availability) than is usually the case in LMIC settings. The sophistication of data collection

in HIC is evident in the widespread use of hospital, regional and national standardised databases, from which information can be extracted and evaluated with confidence for research purposes.

2.7.3.4 *Outcomes*

Of the 12 descriptive papers reviewed, only 2 (both HIC publications) provided a measurement-based definition of contracture (Richard et al., 2017; Richard & Santos-Lozada, 2017). In the LMIC descriptive studies reviewed, outcomes were variably and inconsistently described, making comparisons difficult. All 3 articles based on reconstructive patient populations reported contracture as the sole outcome of interest but the 5 papers reporting on acute burn patients included a wider range of outcomes. The term ‘contracture’ was not defined in any of the papers; one paper used the term “residual disability” as an outcome (Aramani et al., 2010), which included patients with contractures (undefined) and disfiguring scarring. In the 3 reconstructive papers (Kim et al., 2012; Muguti & Fleming, 1992; Saaiq et al., 2012), the requirement for contracture release (as judged by the treating clinician) was deemed to evidence a contracture. There was no measurement of ROM or severity classification of any documented contracture.

The time at which the contracture was captured/noted was not given in the acute burn patient groups; it is assumed that the contracture was noted at some point during their hospital stay, which presents the same concerns as the HIC papers which used hospital discharge as an endpoint. All but two papers reported contractures by patient numbers, although presumably some patients could have had more than one contracture. Other than general and inconsistent documentation of the location of the contracted joint, there is no analysis at joint level in LMIC papers. Only three LMIC papers report on exactly which joints were contracted. There is no analysis or description of

which joints were at risk of contracture. Only two papers accurately document the location of the initial burn; general terms such as “upper limb”, “lower limb”, “face and neck” are more frequently used.

Contracture rates reported in LMIC study populations are fairly low compared with studies from HIC. The four acute care studies reporting contractures demonstrated a prevalence of 12% - 35% although the timing of contracture diagnosis was not stated. This is lower than the prevalence recorded in many HIC papers 7.80% (Pegg et al., 1979), 28% (Dobbs & Curreri, 1972), 82% (Richard et al., 2017)), but may reflect populations with less severe burns overall, poor definition/measurement systems, differing times of measurement, or a context in which patients with more severe burns are more likely to die, thus artificially reducing the prevalence of contractures. The paper with the lowest prevalence of contractures included a high proportion (80%) of patients with only second-degree burns, which would not normally be expected to cause contractures (Dobbs & Curreri 1972).

Unlike publications from HIC settings, 50% (4/8) of LMIC descriptive papers reviewed in this section used photographs to illustrate the contractures. This may have been an attempt to capture the interest of readers, or an effort to illustrate specific features in the absence of defined measurements, or perhaps to demonstrate the severity of complications observed.

Table 2-9: Comparison of patient characteristics in descriptive papers (HICs and LMICs)

Variables Documented		Sources					
	Papers (n=12)	HIC papers (n=4, all acute patients)			LMIC papers (n=8) (acute patients 5, reconstructive patients 3)		
Demographics	N	N	References		N	References	
Gender	11	3	Pegg et al. 1978; Gorga et al. 1999; Richard et al., 2017		8	Sowemino, 1983; Muguti & Fleming, 1992; Ramakrishnan et al. 2004; Aramani et al. 2010; Kim et al. 2012; Saaiq et al. 2012; Ringo & Chilonga 2014; Agbenorku et al. 2015	
Ethnicity	2	2	Gorga et al. 1999; Richard et al., 2017		-		
Age at burn	11	3	Pegg et al. 1978; Gorga et al. 1999; Richard et al. 2017		8	Sowemino 1983; Muguti & Fleming, 1992; Ramakrishnan et al. 2004; Aramani et al. 2010; Kim et al. 2012; Saaiq et al. 2012; Ringo & Chilonga 2014; Agbenorku et al. 2015	
Time since burn	5	2	Gorga et al. 1999; Richard et al. 2017		3	Kim et al. 2012; Saaiq et al. 2012; Ringo & Chilonga 2014	
Weight and height	1	1	Richard et al. 2017		-		
Hand dominance	1	1	Richard et al. 2017		-		
Socioeconomic factors							
Education level	3	2	Gorga et al. 1999; Richard et al. 2017		1	Ringo & Chilonga 2014	
Occupation	2	-			2	Kim et al. 2012; Agbenorku et al. 2015,	
Residence (rural/urban)	2	-			2	Muguti & Fleming 1992; Ramakrishnan et al. 2004	
Neuropathy	1	1	Richard et al. 2017				
Hypertrophic ossification	1	1	Richard et al. 2017				

Table 2-10: Comparison of medical and burn variables in descriptive papers (HICs and LMICs)

Variables Documented	Papers (n=12)	Sources			
		HIC papers (n=4, all acute patients)		LMIC papers (n=8, populations: acute patients 5, reconstructive patients 3)	
Medical Factors	N	N	References	N	References
Pre-existing physical condition	2	2	Pegg et al 1978, Richard et al. 2017	-	
Pre-existing medical condition	2	1	Richard et al. 2017	1	Ringo & Chilonga, 2014
Concomitant injury	1	1	Richard et al. 2017	-	
Previous psychological problem	1	1	Richard et al. 2017	-	
Learning impairment	1	1	Richard et al. 2017	-	
Positive toxicology screen	1	1	Richard et al. 2017	-	
Alcohol +/- drug abuse	1	1	Richard et al. 2017	-	
Burn Factors					
Cause of burn	10	3	Pegg et al. 1978; Gorga et al. 1999; Richard et al. 2017	7	Sowemino, 1983; Muguti & Fleming, 1992; Ramakrishnan et al. 2004; Aramani et al. 2010; Saaiq et al. 2012; Ringo & Chilonga 2014; Agbenorku et al. 2015
Mechanism of injury	6	1	Pegg et al. 1978	5	Sowemino 1983; Aramani et al. 2010; Kim et al. 2012; Saaiq et al. 2012; Ringo & Chilonga 2014; Agbenorku et al. 2015
Depth of burn	7	3	Dobbs & Curreri, 1972; Pegg et al. 1978; Richard et al. 2017	4	Ramakrishnan et al. 2004; Aramani et al. 2011; Kim et al. 2012; Ringo & Chilonga 2014
Location of burn	6	3	Dobbs 1972; Pegg et al. 1978; Gorga et al. 1999	3	Sowemino, 1983; Ringo & Chilonga 2014; Agbenorku et al. 2015
% TBSA (total)	11	4	Dobbs & Curreri 1972; Pegg et al. 1978; Gorga et al. 1999; Richard et al. 2017	7	Sowemino, 1983; Ramakrishnan et al. 2004; Aramani et al. 2010; Kim et al. 2012; Saaiq et al. 2012; Ringo & Chilonga 2014; Agbenorku et al. 2015
% TBSA by depth	2	2	Dobbs & Curreri 1972; Richard et al. 2017	-	
Amputation	1	1	Richard et al. 2017		

Table 2-11: Comparison of treatment variables included in descriptive papers (HICs and LMICs)

Treatment Factors	Papers (n=12)		Source: HIC papers (n=4)	Source: LMIC papers (n=8)	
	N	N		References	N
First aid	1	-			1 Ringo & Chilonga, 2014
Any Rx vs no Rx	2	-			2 Kim et al. 2012; Saaiq et al. 2012
Place of initial Rx	2	-			2 Muguti & Fleming 1992; Saaiq et al. 2012
Nature of initial Rx	3	-			3 Sowemino, 1983; Kim et al. 2012; Saaiq et al. 2012
Time to Rx at hospital	1	-			1 Ringo & Chilonga, 2014
Any surgical procedure	1	-			1 Agbenorku et al. 2015
Escharotomy / fasciotomy	1	1	Richard et al. 2017		-
Skin grafting	4	2	Gorga et al. 1999; Richard et al. 2017		2 Kim 2012; Saaiq 2012
Time to skin graft	1	-			1 Ringo & Chilonga
Graft type	1	1	Richard et al. 2017		-
Graft mesh	1	1	Richard et al. 2017		-
% grafted	1	1	Richard et al. 2017		-
Severity of inhalation injury	1	1	Richard et al. 2017		-
Ventilator use	1	1	Richard et al. 2017		-
Number of days on a ventilator	1	1	Richard et al. 2017		-
LOS in acute care	6	2	Pegg et al. 1978; Richard et al. 2017	4	Sowemino, 1983; Aramani et al. 2010; Ringo & Chilonga, 2014; Agbenorku et al. 2015

Table 2-11: (continued)

Treatment Factors	Papers (n=12)	Source: HIC papers (n=4)		Source: LMIC papers (n=8)	
		References		References	
Healing time	2	1	Gorga et al. 1999	1	Sowemino, 1983
Number of days with bed rest	1	1	Richard et al. 2017	-	
Received oedema control	1	1	Richard et al. 2017	-	
VTE prophylactic treatment	1	1	Richard et al. 2017	-	
Anabolic agent administered	1	1	Richard et al. 2017	-	
Physiotherapy	6	2	Dobbs & Curreri, 1972; Gorga 1999	4	Kim et al. 2012; Saaiq et al. 2012; Ringo & Chilonga 2014; Agbenorku et al. 2015
Patients splinted or positioned	3	2	Dobbs & Curreri 1972; Richard et al. 2017	1	Saaiq et al. 2012
ROM exercises	2	1	Dobbs & Curreri, 1972	1	Saaiq et al. 2012
Days of direct rehab time	1	1	Richard et al. 2017	-	
Days of non-billable rehab time	1	1	Richard et al. 2017	-	
Physiotherapy time (min)/LOS day	1	1	Richard et al. 2017	-	
Physiotherapy time (min)/rehab day	1	1	Richard et al. 2017	-	
Mean splinting/positioning time	1	1	Richard et al. 2017	-	
No of splints/positions	1	1	Richard et al. 2017	-	
Pain tolerance	1	1	Richard et al. 2017	-	
Rehab compliance	1	1	Richard et al. 2017	-	

2.7.3.5 Interchangeable use of factors as outcomes and variables

In clinical practice, outcomes are usually defined in terms of mortality (death) or morbidity. In research, outcomes are the factors measured as endpoints, to which other variables can be related. In the context of burns research, the outcomes are usually considered to be the final results of treatment, including death, scarring, quality of life, disfigurement, contracture, amputation or other medical or psychological morbidities.

However, in some burn outcome evaluations, especially those of contracture, complications of injury or treatment may also be variables which could affect the outcome. It is therefore possible for a specific characteristic (e.g., amputation) to be considered as both a risk variable and an outcome. This inconsistency is evident in the variables and outcomes documented in both the HIC and LMIC descriptive papers reviewed.

Pegg et al. (1978) reported a variety of burn-related or treatment-related complications, including death, as outcomes. However, Richard et al. (2017) and Richard & Santos-Lozada (2017) documented some of the same complications as variables which were examined for impact upon their selected outcome of interest, which was the presence or absence of contracture. Both Pegg et al. (1978) and Richard et al. (2017) documented amputations, but Pegg et al. (1978) used these as outcomes, while Richard et al. (2017) considered amputation to be a variable which could contribute to contracture development. In addition to contracture, Gorga et al. (1999) examined scar severity as a physical outcome, along with other developmental and functional outcomes. It is therefore important to distinguish variables from outcomes when comparing studies.

Table 2-12 summarises the range of morbidity data collected in HIC and LIC descriptive papers, according to whether the morbidity described was used

as a variable or an outcome. Whatever variables and outcome measures are selected, it is crucial that they are accurately and consistently defined.

Table 2-12: Mortality and morbidity data in descriptive papers

Complications Recorded	No. of Papers (n=12)	Used as Variable (HIC papers only)	Used as Outcome	
			HIC	LMIC
Death	6	-	Pegg et al. 1978	Sowemimo, 1983; Aramani et al. 2010; Saaiq et al. 2012; Ringo et al. 2014; Agbenorku et al. 2015
Tracheostomy	1	-	Pegg et al. 1978	
DVT or PE	1	Richard et al. 2017	-	
Pneumonia	1	-	Pegg et al. 1978	
Septicaemia	1	-	Pegg et al. 1978	
Gastrointestinal problems	1	-	Pegg et al. 1978	
Wound infection	5	-	Pegg et al. 1978	Sowemimo, 1983; Aramani et al. 2010; Kim et al. 2012; Ringo et al. 2014
Escharotomy	2	Richard et al. 2017	Pegg et al. 1978	
Exposed burn	2	Richard et al. 2017	Kim et al. 2012	
Exposed tendon	1	Richard et al. 2017	-	
Heterotopic ossification	2	Dobbs & Curreri 1972; Richard et al. 2017	-	
Amputation	4	Richard et al. 2017	Pegg et al. 1978	Ramakrishnan et al. 2004; Agbenorku et al. 2015
Hypertrophic scarring	7	-	Pegg et al. 1978; Gorga et al. 1999	Sowemimo, 1983; Ramakrishnan et al. 2004; Aramani et al. 2010; Saaiq et al. 2012; Agbenorku et al. 2015

Table 2-12: (continued)

Complications Recorded	No. of Papers (n=12)	Used as Variable (HIC papers only)	Used as Outcome	
			HIC	LMIC
Contractures	12	-	Dobbs & Curreri 1972; Pegg et al. 1978; Gorga et al. 1999; Richard et al. 2017	Sowemimo, 1983; Muguti & Fleming 1992; Ramakrishnan et al. 2004; Aramani et al. 2010; Kim et al. 2012; Saaiq et al. 2012; Ringo et al. 2014; Agbenorku et al. 2015
Neuropathy	2	Dobbs 1972, Richard et al. 2017	-	-
Brain injury	1	Dobbs & Curreri 1972	-	-
Rehabilitation needed	2	Richard et al. 2017	-	Ramakrishnan et al. 2004
Blindness	1	-	-	Agbenorku et al. 2015
Psychiatric or psychological morbidity	2	Richard et al., 2017	-	Ramakrishnan et al. 2004
Acute LOS	4	Richard et al. 2017	-	Sowemimo, 1983; Aramani et al. 2010, Ringo 2014,
Developmental delay	1	Gorga et al. 1999	-	-
Functional loss	1	Gorga et al. 1999	-	-
Other morbidity unspecified	3	-	-	Sowemimo, 1983; Ramakrishnan et al. 2004; Aramani et al. 2010,

2.7.4 Conclusions from Review of Descriptive Papers

A wide range of actual or potential risk factors for various adverse burn outcomes, including contracture, was reported. A number of these were believed or assumed by authors to be directly or specifically related to contracture development, but only a limited number of papers actually provided any supporting data.

Table 2-13 lists the factors for which any data were provided to support a possible association with contracture development; none have been demonstrated to be statistically significant and unfortunately many of the descriptors are subjective. For the factors reported by Richard et al. (2017), who described a patient profile associated with NO contracture, the converse factors have been included as potential risk factors FOR contracture. Similarly, some authors noted that lack of an intervention or treatment was more likely to be associated with contracture development.

The potential risk factors identified have been categorised in keeping with previous tables. It should also be noted that there is some overlap. For example, skin grafting may be considered by some authors to be synonymous with a deep burn, and therefore a risk, while others consider lack of grafting to be a risk. Similarly, the term ‘physiotherapy’ is general and may include splinting, positioning and other modalities, or may be used interchangeably with ‘rehabilitation’.

Nevertheless, this list of possible risk factors adds to the knowledge provided by more robust evidence and expands the range of variables which may be worthy of inclusion in the proposed data collection tool for the present study.

Table 2-13: Potential risk factors for contracture from descriptive papers

Possible Risk Factors	Source	
Patient Factors	HIC	LMIC
Female gender	Pegg et al. 1978	
Lack of education	Richard et al. 2017	
Associated co-morbidity	Richard et al. 2017	
Psycho-social problems	Richard et al. 2017	
Burn Factors		
Deep burn	Dobbs & Curreri, 1972	Armani et al., 2010
Flame burn		Muguti & Fleming, 1992; Armani et al. 2010; Saaiq et al. 2012
Larger TBSA	Dobbs & Curreri, 1972; Richard et al. 2017	
Treatment Factors		
Incomplete initial burn care		Muguti & Mhaka, 1994; Saaiq et al. 2012; Kim et al. 2012
Treatment in rural healthcare		Muguti & Mhaka, 1994
Delayed referral to specialist care		Muguti & Fleming, 1992, Muguti & Mhaka, 1994
Lack of skin grafting		Muguti & Mhaka, 1994, Saaiq et al. 2012; Kim et al. 2012
Larger skin grafted area	Richard et al. 2017	
Complicated hospital course	Richard et al. 2017	
Inadequate hospital stay	Richard et al. 2017	
Lack of physiotherapy		Saaiq et al., 2012; Kim et al., 2012
Lack of splinting		Saaiq et al. 2012; Kim et al. 2012
Delayed physiotherapy	Dobbs & Curreri, 1972	Muguti & Mhaka, 1994; Ringo et al. 2014
Lack of daily rehabilitation time	Richard et al. 2017	
Low ratio of rehabilitation to hospital days	Richard et al. 2017	
Low pain tolerance	Richard et al. 2017	
Low compliance with rehabilitation	Richard et al. 2017	

2.8 INTERVENTION STUDIES

2.8.1 Introduction

The literature search identified 17 papers addressing the impact of a variety of specific non-surgical therapeutic interventions on the presence and severity of contracture. If an intervention has been demonstrated to reduce the prevalence of contracture after burn, then the absence or lack of that intervention during treatment could be a risk factor for contracture formation.

Papers which examine such interventions and use contracture as an outcome are included in this section. Surgical interventions to reconstruct a contracture are not included. Case reports or small series with less than five subjects in the study have also been excluded from review here but are included in a later section on Putative Risk Factors if authors assert opinions on, or state the existence of, any risk factors.

Four systematic reviews of the effect of physiotherapy interventions on contractures, including those in burns patients (Flores et al., 2018; Harvey et al., 2017; Katalinic et al., 2008; Zhang et al., 2017) and one literature review (Schouten et al., 2012) were identified. The Cochrane review on the impact of stretch by Katalinic et al. (2010) only included burns patients previously reviewed by Fergusson et al. (2007) which has already been discussed in this chapter. An updated Cochrane review on the effect of stretch in contractures was published by Harvey (2017) and is discussed here as it includes some additional patients with burn contractures. Zhang et al. (2017) also reviewed the effect of mechanical stretch interventions on burns and scars. The final systematic review identified was a meta-analysis of the effects of different forms of exercise on a range of patient outcomes following burns, including the need for surgical release of contractures (Flores et al., 2018).

The literature review included addressed the benefits of static splinting in preventing burn contractures (Schouten et al., 2012); two subsequent letters challenged some of the conclusions of that review (Parashar et al., 2013) (Richard et al., 2013) and are also discussed below. A further 10 individual studies investigating the impact of individual therapeutic interventions on burn contractures are also reviewed in this section.

2.8.2 Systematic Reviews

Two of the 3 systematic reviews addressed the impact of stretching interventions on contractures (Harvey et al., 2017; Zhang et al., 2017.). Flores et al. (2018) examined the effects of exercise on physical, physiological and psychological outcomes in post-burn patients. The main features and findings of the systematic reviews are summarised in Table 2-14. Overall, no conclusive evidence of benefit was found for stretching therapies in post-burn patients with contractures. Although Zhang (2017) concluded that 3/5 papers demonstrated significant reduction in contracture severity (Godleski et al., 2013; Morien et al., 2008; Okhovatian & Zoubine, 2007) differences in contracture measurements and stretching regimens employed by the studies made the evidence inconclusive. Only 2 of the 49 studies examined by Harvey et al. (2017) related to burns patients (Deng et al., 2016; Kolmus et al., 2012); these studies were not analysed separately with respect to benefits of stretching on contracture outcome. The overall finding of the Cochrane review was that there was high quality evidence that stretch performed for less than seven months (the time frame for which data was available) did not have clinically important effects on joint mobility for all aetiologies explored (Harvey et al., 2017).

Table 2-14: Summary of systematic reviews of non-surgical therapies for contractures

Source	Intervention(s) Studied	Population Included	No. of Papers Included	Sample Size	Main Findings	Intervention Beneficial for Contracture?
Harvey et al. 2017	Stretching therapy for up to 7 months (by sustained passive stretch, positioning, splinting or cast)	Adults with contractures due to various neurological or non-neurological conditions (including burns)	49 RCTs; 2 on burns patients	2135; 76 burns	Short term (<7 months) stretching had no impact on contractures	No
Zhang et al. 2017	Mechanical stretching, massage and splint	Children/adults with post-burn hypertrophic scars	9 (5 RCTs, 4 non-RCCT); all on burns patients	375, all post-burns, various locations	Significant benefit from stretch in 3/5 papers using contracture as outcome	Possibly, but inconclusive due to confounding factors and varying regimens of stretching
Flores et al. 2018	Exercise modalities (including aerobic +/- resistance, vibration, isokinetic, coordination and strength, range of motion, and video game-assisted exercises)	Children/adults	19; only 2 using contracture as outcome ³	669; all post-burn, various locations	Exercise regimens improve some physical, physiological and psychological outcomes after burns, but quality of evidence poor	Yes, in 2 papers using contracture release as outcome but quality of evidence poor and imprecision very serious

Exercise, particularly aerobic exercise with resistance, was found to be associated with a significant reduction in the need for contracture release in the meta-analysis by Flores et al. (2018). However, the reviewers emphasised the low quality of evidence and a high degree of imprecision overall, particularly in relation to the use of the need for surgical contracture release as an outcome. Therefore, the conclusion that exercise is beneficial in preventing or reducing burn contractures must be viewed with caution.

2.8.3 Literature Review

Schouten et al. (2012) published a literature review on the use of static splinting in the prevention of burn scar contracture. The authors based their review on an electronic search of publications, from an undefined start date to April 2010, which addressed a wide range of contracture-related issues including general burns papers, studies of treatments and rehabilitation and basic science experimental studies on burns and wound healing. Their aim was to consolidate current knowledge which could underpin the design of future randomised controlled trials of splinting therapy in burn patients. The number of publications identified, retrieved, and reviewed was not documented and no details were given on why or how articles may have been judged irrelevant and excluded from the review.

This paper focuses mainly on reported incidence of contracture and the possible mechanisms of static splinting at the cellular and molecular level. The main conclusion of the article is that although splinting is a core treatment in the prevention of burn contractures, there is no good quality evidence that static splinting can prevent scar contracture. Furthermore, based on their review of the literature into potential mechanisms at cellular level in response to stretch, they propose that there is evidence that mechanical tension during wound healing can upregulate myofibroblasts, leading to increased

production of collagen and scarring. They concluded that static splinting could worsen scar contracture formation and counteract its own purpose. The authors therefore supported the need for a randomised controlled trial (RCT) on the impact of splinting.

The authors also noted the wide variation in reported contracture rates, and the fact that contractures appear to be dynamic, with different rates evident at different times of assessment. This is also a feature which has been apparent through the present literature review, and which often confounds efforts to identify risk factors for contracture.

They also emphasised the need for a standardised method of contracture measurement and definition of contracture, which are both currently lacking in clinical practice. This is also highly relevant to the present study because identification of risk factors is dependent on consistent and valid definitions and measures of contracture.

Schouten et al., (2017) concluded that the prevalence of contractures was unclear, and stated, “it is difficult to identify the real extent of the problem and to compare the outcome of different anti-contracture interventions” (p. 47). This statement is equally relevant to the search for other significant risk factors for contracture in the present study.

The review by Schouten et al. (2012) stimulated two responses in Letters to the Editor (Parashar et al., 2013; Richard et al., 2013). Both responses confirmed the need for further rigorous investigation of the impact of commonly used splinting. One response from India (Parashar et al., 2013) referred to the effective use of splints in the paper by Huang and presented a strong opinion that splinting was beneficial, based on clinical experience. Parashar et al. (2013) stated, “It has been consistently observed in clinical setting that static splintage

started early and continued for prolonged period of time after grafting, followed by ROM exercises is the most effective therapy for prevention of contractures” (p. 190). The authors viewed any failure of splintage as a result of improper application or non-compliance. They also suggested that a RCT trial could have ethical ramifications if applied universally. This view is important, as splinting may have greater significance in LMICs where other supporting treatments (such as early skin grafting, pain management and necessary infrastructure) are lacking. Results of splinting RCTs in HICs may not be automatically transferable to LMICs.

The second response (Richard et al., 2013) presented the results of a re-analysis of data from two articles, both included in this review, (Bunchman et al., 1975; Huang et al., 1978) showing the statistically significant impact of splint use in neck contractures and the need for splints to be worn for a minimum of 6 months. The author supported the call for a RCT on splinting.

2.8.4 Other Papers on Non-surgical Interventions for Contracture

Of the 10 interventional studies, four papers examined the benefits of splinting and/or pressure in the prevention of burn contracture (Bunchman et al., 1975; Huang et al., 1978, Kolmus et al., 2012; Richard et al., 2000,); all were from HIC settings. Six studies examined the impact of various exercise regimes on the incidence and severity of burn contractures in adults and children (Celis et al., 2003; Deng et al., 2013; Karimi et al., 2013; Neugebauer et al., 2008; Okhovatian et al., 2007; Paratz et al., 2012). Of these, 2 were from Iran (Karimi et al., 2013; Okhovatian et al., 2007) and one was from mainland China (Deng et al., 2016); these are classified as Upper Middle-Income Countries by the World Bank 2019 (Netherlands for the World Bank, 2019). The remaining 3 exercise studies were from the USA. None of the intervention studies were from LIC or LMIC settings.

The key features of the four splinting/pressure studies are summarised in Table 2-15 below. Only one was prospective (Kolmus et al., 2012). The measured outcomes and findings are summarised in Table 2-16. Two studies examined single joints only – the neck (Bunchman et al., 1975) and axilla (Kolmus et al., 2012). Only one study measured ROM in assessing contracture (Kolmus et al., 2012); others relied on clinical assessments.

The results of these studies were mixed. Three studies (Bunchman et al., 1975; Huang et al., 1978; Richard 2000) claimed to show significant improvements in joint movements after splint use but noted that it was important that the splint be worn consistently for a minimum of 6 months and preferably >12m. That patients found this difficult was evidenced by significant fall-out rates before study periods ended. Richard et al. (2013) re-analysed the results of Bunchman et al (1975) and Huang et al (1978) in a Letter to the Editor which has been described previously (Richard 2013). In that letter the importance of duration of splinting was emphasised.

Kolmus et al. (2012) found no benefit from axillary splinting at any of the time-points examined; however, they acknowledged the poor compliance in the intervention group. This was postulated to be due to discomfort of wearing the splint or to the patient believing they had no need of the splint any longer.

Table 2-15: *Splinting/pressure intervention studies: Summary of type of study, population and intervention*

Source	Location and Type of Study	Population	Sample Size	Intervention Studied
Bunchman et al. 1975	USA; retrospective, descriptive	Patients with 3 rd degree neck burns post 1968 cf pre-1968 (historical controls)	128 (98 had intervention)	Effect of cervical splint for minimum 6 months
Huang et al. 1978	USA: retrospective, descriptive	All inpatients with burns to axilla, elbow, wrists, and knees during study period	625 patients, 1235 joints at risk	Length of splint and pressure use / time period of use (none, <6 months, 6-12 months, >12 months)
Richard et al. 2000	USA; retrospective, multisite + meta-analysis of selected literature	Children and adults with contractures treated non-surgically	31 children, 21 adults	Multimodal (massage, exercises, pressure) vs “progressive” (single intervention, static or dynamic splint or serial cast)
Kolmus et al. 2012	Australia: prospective single centre RCT over 2 years	Adults admitted acutely with: <ul style="list-style-type: none"> - Axillary burns requiring surgery - no co-morbidity or shoulder injury - < 50% TBSA 	52 (27 in intervention group)	Splinting of the axilla @ 90° for 12 weeks Both control and intervention groups also had 12-weeks shoulder exercises/stretching

Table 2-16: Splinting/pressure intervention studies: Outcomes and significant findings

Source	Intervention Studied	Outcomes/endpoints Documented	Intervention Assessment	Significant Findings	Comments or Observations
Bunchman et al. 1975	Neck collar (splint) use for minimum 6 months	Incidence and severity of contracture + need for contracture release	Clinical assessment	Reduced incidence and severity of neck contracture with neck splint	Observational study, limited data (data reanalysed by Richard, 2013)
Huang et al. 1978	Effect of splint and pressure on contractures in various joints	Severity of contracture Surgical interventions Duration of using splint/pressure	Medical records, clinical assessment	Incidence of contracture and need for surgical release significantly reduced in splint/pressure patients, provided splints worn for minimum 6 and ideally >12m	12.5% non-compliance in wearing splint (data reanalysed by Richard, 2013)
Richard et al. 2000	Multimodal physiotherapy vs splinting or cast	Contracture resolution time	Descriptive, clinical assessment, no measurements	Some contractures corrected by non-surgical Rx alone. Splinting/casts result in faster resolution of contracture than multimodal Rx	Patient origin not clear, groups not totally comparable, 25% contractures in hand, very small numbers
Kolmus et al. 2012	Axillary splinting for 12 weeks	Measured ROM of the axilla (flexion and abduction) using Plurimeter-V Inclinometer on admission, and at 6 and 12 weeks	ROM Splint adherence	No significant benefit from intervention with respect to ROM at any stage of assessment Very poor compliance with splint use for various reasons	Patients in intervention group had slightly better ROM from outset. High quality of additional supportive care and rehab, so results may be different elsewhere e.g., in LMIC

Six publications addressed the use of exercise regimes in reducing the incidence and/or severity of post-burn contractures (Celis et al., 2003; Deng et al., 2016; Karimi et al., 2012; Neugenbauer et al., 2008; Okhovatian et al., 2007; Paratz et al., 2012). These studies are summarised in Table 2-17 and the outcomes are shown in Table 2-18. Two studies were exclusively paediatric (Celis et al., 2003; Neugenbauer et al., 2008); the rest were either adult only or mixed populations.

Most of the interventional studies categorised contracture severity. Bunchman et al. (1975) classified severity based on the extent of surgery required. The remaining studies (Deng et al., 2016; Dobbs & Curreri, 1972; Huang et al., 1978; Kolmus et al., 2012; Neugebauer et al., 2008; Richard et al., 2000) used degrees of movement measured by a goniometer or eyeball assessment of severity; 3 of these papers (Dobbs and Curreri, 1972; Huang et al., 1978; Karimi et al., 2013) converted the ratio of $\frac{\text{observed degrees of ROM}}{\text{expected degrees of ROM}}$ into a severity scale to indicate mild, moderate and severe contractures.

A variety of exercise regimes were examined. The paediatric studies used age-appropriate exercise (Celis et al., 2003; Neugenbauer et al., 2008), the adult studies were very diverse in the nature of the exercise modalities employed, the outcome measures and the duration of follow-up. The studies claimed to demonstrate a significant benefit from exercise regimes in addition to standard physiotherapy/rehabilitation protocols. This finding was supported by the systematic review of Flores et al. (2018); although, the quality of evidence was assessed to be poor and the potential for imprecision in assessment was great.

However, as both splinting and exercise have been shown to be potentially beneficial in preventing contractures, lack of these interventions could be included as potential risk factors for contracture in the present study.

Table 2-17: Exercise intervention studies: Summary of type of study, population and intervention

Source	Location and Type of study	Population	N	Intervention Studied
Celis et al. 2003	USA; prospective randomised	Children aged 7-19 years with severe burns >40% TBSA	53 children (intervention group =27)	12-week hospital-based resistance and endurance exercise programme @6m post burn (PTEX) vs standard therapy Rx
Okhovatian & Zoubine, 2007	Iran; prospective, matched, randomised controlled	All burn admissions	30 (15 in each group)	Standard vs intensive burn rehabilitation programme including stretch and exercise Rx
Neugenbauer et al. 2008	USA; descriptive, cohort, non-randomised	Children aged 2-6 years	24 (intervention group = 15)	12-week hospital-based group music and exercise programme from discharge from ITU (GMEP) vs standard PT/OT
Paratz et al. 2012	USA; Prospective, descriptive quasi-experimental, non-randomised controlled	Adults >20% TBSA after final grafting	26 (intervention group =14)	Supervised aerobic and resisted exercise program
Karimi et al. 2012	Iran; prospective case-control study	Adults and children with hypertrophic scars following grafts for burns	64; 31 in intervention group	Effect of intensive physiotherapy and exercise vs standard Rx of pressure garment and silicone
Deng et al. 2016	China; retrospective cohort study	Adult Burns ICU patients with >50% burns	73 (24 in intervention group)	Active mobility training (active ROM exercises, transfer training, tilt table training, and progressive ambulation) vs passive regimen (including anti-contracture positioning, splinting and passive ROM exercises)

Table 2-18: Exercise intervention studies: Outcomes and significant findings

Source	Intervention Studied	Outcomes/endpoints Documented	Intervention Assessment	Significant Findings	Comments or Observations
Celis et al. 2003	12-week resistance & endurance exercise programme	Need for surgical intervention to correct contracture	6 monthly clinical assessments and goniometry	Significantly fewer contractures requiring surgery in intervention group after 12 months	Numbers very low at later stages of follow-up. Not clear if any patients had multiple surgeries
Okhovatian & Zoubine, 2007	Intensive rehabilitation including stretch and exercise	LOS and incidence of contractures, and thrombosis at acute discharge	Clinical records: contracture defined as loss of ROM measured by goniometer	Incidence of contracture significantly reduced in intervention group at discharge	Early assessment at hospital discharge (mean 22d vs 26d in control)
Neugenbauer et al. 2008	12-week music and exercise programme	AROM and PROM of elbows and knees at 3,6,9,12,18,24months	Goniometer measurements	Significantly better ROM in some movements of certain joints in intervention group	"Controls" heterogeneous, joints at risk not clearly specified, loss of ROM varied
Paratz et al. 2012	Supervised aerobic and resisted exercise program	Fitness, muscle strength, upper limb function, health quality of life, need for contracture release before and at intervals	Various measures of fitness, function and quality of life at 6 weeks and 3 months. No ROM data.	Intervention group required fewer contracture releases despite greater burn depth and severity	No contracture measurement, limited follow up (3m), small numbers, heterogeneous groups

Table 2-18: (continued)

Source	Intervention Studied	Outcomes/endpoints Documented	Intervention Assessment	Significant Findings	Comments or Observations
Karimi et al. 2012	Effect of intensive physiotherapy and exercise vs standard Rx of pressure garment and silicone	Scar appearance and joint ROM after 20months	Scar appearance and joint ROM every 4-6 weeks for 20months	Reduced severity of loss of ROM and improved scar appearance in physiotherapy/exercise group cf PGT/silicone	No baseline measurements, intervention patients self-selected, joints at risk not documented, confusion in description of cases vs control
Deng et al. 2016	Active mobility training vs passive regimen	LOS in BICU and hospital, duration of bedrest, rehab time in BICU, ROM of affected joints and ADL at discharge from ICU	Goniometer joint measurements + Bartel Index assessment of activities of daily living	Some movements improved in intervention group	Measurements within 7 days of discharge from ICU

2.9 PUTATIVE RISK FACTORS

As has been shown in previous sections of this chapter, hard evidence for risk factors for post-burn contractures is limited and variable. As the purpose of this literature search and review was to cast a wide net to capture as many potential risk factors for contracture as possible, especially in LMIC settings, it was felt appropriate to include papers which stated assumed or believed contracture risk factors, with or without supporting evidence or references; such factors have been termed putative risk factors.

This section reviews papers quoting or stating commonly accepted or supposed risk factors for burn contracture formation. Most risk factors cited are based on clinical opinion and are unreferenced by the authors. The putative risk factors identified are presented in Table 2-19 and annotated according to whether the factor is 'opinion' or 'evidence-based'.

The term 'opinion' is used to mean that the stated risk factor is not referenced or is referenced only to another opinion. Evidence is recorded when a statement referenced primary research in which data was presented to support the conclusion. Although the term 'evidence-based' is used, this does not attempt to validate the research referenced, but simply denotes that the risk factor cited was derived from original research. If the primary research referenced met the inclusion criteria of this literature review, it has been separately reviewed elsewhere in this chapter. If the original research referenced did not support the risk factor reported or cited another opinion, then the risk factor identified is classified as opinion. Differentiation is made between evidence (from original research) and descriptive papers. The term 'Descriptive' refers to citation of descriptive studies to support the stated risk factor.

Most papers from which putative risk factors are extracted are articles describing general burn care management or burn rehabilitation. These publications often state risk factors for contracture in their introduction, discussion, and/or conclusion, even without references, data, or direct relevance to the focus of the paper. While these do not represent any evidentially based arguments, arguably such statements reflect common beliefs amongst burn care professionals as to the factors that influence burn contracture formation.

Included in these papers are eight studies in which some data are reported. However, these papers did not meet the inclusion criteria of preceding sections for one or more of the following reasons: they are case studies, contracture was not used as an outcome, studies are mixed with non-burn contractures, or the actual method of measurement of contracture is the focus of the paper.

In Table 2-19, papers are also categorised according to the main topic and the geographical source (HIC/LMIC). Collaboration between high- and low-income sources is noted as is the profession of the first author. All papers included in this section were written by clinicians, with a very strong predominance of doctors. Without exception, papers from LMICs were authored by doctors.

Table 2-19: Papers citing or stating putative risk factors for contracture

Focus of Article	No. of Papers (n=47)	HIC Papers (n=37)	LMIC Papers (n=10)
Burn contracture prevention or treatment	4	Beekman, 1929 (Dr.); Coakley, 1937 (Dr.); Larson et al. 1971(Dr.); Buescher & Pruitt Jr, 1994 (Dr.)	
General burn care	6	Penberthy & Weller, 1939 (Dr.); Conway, 1964 (Dr.); Atiyeh et al., 2005 (Dr.) Spanholtz et al. 2009 (Dr.); Marchalik et al. 2018 (Dr.)	Tyson et al. 2013 (Dr.) *
General burn therapy	14	Koepke, 1970 (Dr.); Curreri et al., 1970 (Dr.); Birch et al., 1976 (Dr.); Lamberty & Whitaker, 1981 (Dr.); Wright, 1984 (PT); Hurren, 1995 (Dr.); Richard & Johnson, 2003 (PT); Esselman et al. 2006 (Dr.); Spires et al., 2007 (Dr.); Serghiou et al., 2009 (OT); R. Richard et al. 2009 (PT); Dewey et al. 2011 (PT); Williams & Berenz, 2017 (OT); Young et al. 2019 (Dr.)	
Reconstructive surgery	6	Davoodi et al. 2008 (Dr.); Barbour et al. 2008 (Dr.)	Adu, 2011(Dr.); Farkhad et al. 2013 (Dr.); Garcia et al. 2016, 2015* (Dr.); Dhakad et al. 2019 (Dr.)
Measurement of contracture	4	Leblebici et al. 2006 (Dr.); R. L. Richard et al. 2009 (PT); Ehanire et al. 2013 (Dr.)	Cai et al. 2016 (Dr.) *
Pathophysiology of contracture	3	Rudolph, 1980 (Dr.); Harrison & MacNeil, 2008 (Dr.) Gauglitz et al. 2011 (Dr.)	
Acute phase burn surgery	2		Durrani, 1973 (Dr.); Prasanna et al. 1994 (Dr.)
Specific therapeutic interventions (splint, casting, pressure, scar management)	8	Surveyer & Clougherty, 1983 (Nurse); Barnett & Stafford, 1984 (PT); Hegel et al. 1986 (Psyc.); Carr-Collins, 1992 (OT); Johnson & Silverberg, 1995, (PT); Richard et al. 1996 (PT)	Haq & Haq, 1990 (Dr.); Puri et al. 2013 (Dr.)

*Collaboration between HIC/LMIC authors

First author profession Dr.=doctor/surgeon, PT=physiotherapist, OT=occupational therapist, Psyc. = psychologist

Risk factors within these papers are often presented in short statements, usually without references. Little detail is added to statements about risk factors, for example, 'lack of splinting' may be cited as a risk factor without any further detail on the type, timing, or duration of splinting.

The papers specifically looking at burn contracture (n=4) are amongst the oldest publications; perhaps at that time the standards of burn care meant contractures were more problematic. Despite the vast problem of burn contractures in LMICs (Saaiq et al., 2012; Sowemimo, 1983), there are no LMIC papers on pathophysiology of contracture. Six of ten LMIC papers were surgically focussed, particularly with reference to reconstructive surgery for burn contractures.

Amongst the articles included in this section, 32 general risk factor topics and 83 more specific putative risk factors were identified. These are presented in Table 2-20. The column labelled 'Topic', relates to the type of factor which was cited. Often no further detail was provided; if provided, the further detail is documented in the column entitled 'Risk Factor'. This column seeks to clarify the specific risk factor, which may be termed as either present or absent: e.g., lack of splinting or presence of a deep burn. The column labelled 'Source' refers to whether the stated risk factor has been classified as opinion or evidence based. The N column indicates the number of times that particular risk factor is reported or cited in the 47 papers reviewed, either as opinion or 'evidence based'. The final column indicates whether the opinion or evidence is from a paper which is from a HIC or LMIC.

Table 2-20: Putative risk factors identified from the literature review

Topic	Risk Factor	N	Source		Origin
Patient Factors					
Age	Growth in children	7	Evidence based		HIC
	Younger age (childhood)		Descriptive	5	HIC
			Opinion	2	
Gender	Female	1	Opinion		HIC
Education	Lack of education	1	Opinion		LMIC
Poverty	Poverty	1	Evidence based		LMIC
Ignorance	Ignorance	1	Opinion		LMIC
Pre-existing disease	Pre-existing disease	1	Evidence based		HIC
Non-compliance	Lack of compliance to treatment	2	Evidence based		LMIC
			Evidence based		HIC
Burn Injury Factors					
Cause of burn	Cause of burn	1	Descriptive		HIC
TBSA	Higher TBSA	9	Evidence based		4
			Evidence based		1
			Opinion		4
Cutaneous Functional Units	Location and number of Cutaneous Functional Units		Opinion		1
Depth of burn	Deep burn	13	Evidence		1
	Depth of burn (what depth is not clarified; implication is deep burn)		Opinion		
	Depth of burn (what depth is not clarified; implication is deep burn)		Opinion		5
	Deep burns given conservative treatment		Opinion		2
	Deep burns close to the proximal joint line		Opinion		HIC

Table 2-20: (continued)

Topic	Risk Factor	N	Source	Origin
Burn Injury factors (cont.)				
Depth of burn (cont.)	Partial and full thickness burns if not excised and grafted	15	Opinion	1 HIC
	Partial and full thickness burns		Opinion	1 LMIC
	Full thickness burns		Evidence	1 HIC
Location of burn / scar	Location of burn	15	Opinion	4 3HIC, 1 LMIC
	Smaller joints		Opinion	1 HIC
	Longitudinal scar bands over the flexor or extensor aspects of joints		Opinion	1 HIC
	Scarring across joint		Opinion	4 HIC
	Burn injury above or below the joint		Opinion	1 LMIC
	Neck, axilla, hand, knee burns		Evidence based	1 HIC
	Burn over the hip joint		Opinion	1 HIC
	Circumferential extremity burn		Opinion	1 HIC
	Which Cutaneous Functional Units is involved		Evidence based	1 HIC
	Thick scars		Opinion	1 HIC
Type of scarring	Excessive scarring	4	Opinion	2 HIC
	Mature, tight and thick scars		Opinion	1 HIC
Fear	Fearful patient	1	Opinion	1 HIC
Pain	Patient maintaining a flexed position to avoid pain	2	Opinion	2 HIC
Muscle loss or weakness	Muscle loss or weakness	1	Opinion	1 HIC
Time post burn	Acute phase of burn care	1	Opinion	1 HIC

Table 2-20: (continued)

Topic	Risk Factor	N	Source	Origin	
Treatment factors: Medical/Surgical					
Wound healing	Open wounds	1	Opinion	LMIC	
	Delayed wound healing	5	Opinion	HIC	
	Healing by secondary intention	4	Opinion	2 LMIC	
			Evidence (based on wound contraction not contracture)	2 LMIC	
	Tension on wounds	1	Opinion	LMIC*	
	Granulating wound bed over joints	1	Opinion	HIC	
Infection	High mobility wound bed	1	Opinion	HIC	
Oedema	Infection	1	Opinion	HIC	
Skin grafting	Oedema	1	Opinion	HIC	
	Lack of skin grafting	2	Opinion	1 LMIC	
	Lack of skin grafting for deep burns			1 HIC	
	2	1 LMIC			
	Delayed grafting	2	Opinion	1 HIC	
Scar management	Split skin graft rather than full thickness graft	2	Evidence	HIC	
	Cryosurgery prevents contracture	1	Opinion	HIC	
	Laser prevents contracture	1	Opinion	HIC	
	Steroid injection prevents contracture	1	Opinion	HIC	
	Antihistamines prevents contracture	1	Opinion	HIC	
	Mechanical devices	1	Opinion	HIC	
	Aggressive scar management prevents contracture	1	Opinion	HIC	

Table 2-20: (continued)

Topic	Risk Factor	N	Source		Origin
Treatment Factors: Therapy					
Therapy	Lack of physiotherapy	7	Opinion	4	2 HIC, 2 LMIC
			Descriptive	2	LMIC
			Evidence	1	HIC
Positioning	Delayed physiotherapy	3	Opinion	2	1 HIC 1 LMIC
			Descriptive	1	LMIC
			Opinion	3	LMIC
Mobilisation	Lack of positioning	14		11	HIC
		Descriptive	1	LMIC	
	Early mobilisation prevents contracture	3	Opinion	3	HIC
Exercise	Prolonged Immobilisation/bed rest	4	Opinion	4	HIC
	Promotion of independence in functional tasks prevents contracture	1	Opinion	1	LMIC
	Lack of exercise	5	Opinion and descriptive	1	LMIC
Exercise	Active exercise prevents contracture	3		4	HIC
	ROM exercise prevents contracture	1	Opinion		HIC
	Regular exercise through full range of movement prevents contracture	2	Opinion		HIC
	Active and passive exercise prevents contracture	1	Opinion		HIC
	Passive ROM in theatre prevents contracture	1	Opinion	1	HIC
	Prolonged Stretch prevents contracture	3	Opinion	2	HIC
			Evidence	1	
	Lack of hydrotherapy	1	Opinion	1	HIC

Table 2-20: (continued)

Topic	Risk Factor	N	Source	Origin
Treatment Factors: Therapy				
Splinting	Lack of splinting	48	Opinion	27 HIC 10 LMIC
			Descriptive	1 HIC 3 LMIC
			Evidence	7 HIC 1 LMIC
Scar massage	Lack of scar massage	2	Opinion	2 HIC
Lack of pressure garments	3	Opinion	3 HIC	
Pressure	Pressure garments for several months after grafting prevents contracture	1	Opinion	1 HIC
	Pressure garments for 6-12 months prevents contracture	1	Evidence	1 HIC
	Pressure garments worn 22 hours a day for 12-18 months prevents contracture	1	Descriptive	1 LMIC
Silicone	Lack of silicone	2	Opinion	1 HIC
Healthcare System Factors				
Healthcare system	Lack of healthcare facility utilization /failure to seek care	3	Opinion	3 LMIC
	Lack of healthcare facilities	3	Opinion	3 LMIC
	Ineffective treatment	7	Opinion	6 LMIC 1 HIC
	Lack of follow up	1	Opinion	1 LMIC

2.9.1 Summary of Identified Putative Risk Factors

Most of these accepted, assumed, or presumed risk factors are very general, non-specific, largely unconfirmed by any data (referenced or otherwise) and emanate from HIC publications. Table 2-21 shows the distribution of opinion-based vs evidence-based sources of quoted putative risk factors from HIC and LMIC contexts. References citing an evidence base (including descriptive studies) are in the minority in both HIC (21%) and LMIC (11%) publications, but particularly in those from LMIC sources.

Table 2-21: Distribution of opinion vs evidence-based putative risk factors

HIC Sources		LMIC Sources	
Opinion	135	Opinion	42
Evidence	29	Evidence	5

Table 2-22 shows the most frequently cited risk factors, again by origin. Lack of splinting is the most cited risk factor for burn contracture in all categories. However, other than lack of positioning, the other four top ranking risk factors in LMIC papers are totally different from the HIC-cited risk factors i.e., only 2/6 top risk factors are the same in both the LMIC and HIC categories.

Table 2-22: Top 6 most frequently cited putative risk factors for contracture

HIC	n	LMIC	n
Lack of splinting	34	Lack of splinting	13
Location or position of scar	14	Healing by secondary intention/lack of graft	8
Depth of burn	12	Ineffective treatment	7
Lack of positioning	11	Lack of healthcare facilities	3
High TBSA	9	Lack of positioning	3
Younger age	6	Lack of physiotherapy	3

The popularity of splinting (and the lack of splinting as a risk factor) in this section of literature is striking and possibly surprising, considering the limited

evidence on splinting after burn injury for contracture prevention. However, there is clearly a strong clinical belief that splinting is very important in risk reduction for burn contracture formation.

It is of interest to note that 3 out of 6 risk factors most highly cited in the LMIC literature related to lack of therapy input (lack of splinting, lack of positioning, lack of physiotherapy). There is virtually no evidence to demonstrate the impact of positioning, but this also features highly in cited putative risk factors.

It is notable that depth and TBSA of burn, variables that feature commonly in studies trying to identify risk factors, are not in the list of most frequently cited risk factors in the LMIC context (Table 2-22). Burn depth is the third most common and TBSA the fifth most cited risk factor in HIC papers, after lack of splinting, location or position of scar and lack of positioning. Second in frequency for LMIC-cited putative risk factors is healing by secondary intention/skin grafting – these may be a proxy for deep burns but are referred to in this way because deep burns are normally excised and grafted in the HIC context. Another remarkable feature is the commonly cited factors of location or position of scar in the HIC papers, as these also do not feature so highly in the earlier categories of publications.

Many studies do not discuss how joints at risk are defined or whether the anatomical location of a joint may have an impact on the risk of burn contracture formation. The reasonably low frequency with which young age was cited as a risk factor was unexpected, considering that, like TBSA and depth of burn, age often featured as a risk factor in the descriptive and interventional studies reviewed. Several notable risk factors do not feature in the list of putative factors but were found to be significant in some risk factor

studies, such as ethnicity, escharotomy, amputation, length of stay, inhalation injury, and length of stay in intensive care.

Four of the top 6 risk factors from LMIC papers are not mentioned in the top 6 from HICs and are of interest as they relate to deficiencies in care which might be taken for granted in a HIC setting. This highlights the importance of taking a holistic view when looking for risks, otherwise issues not relevant or controlled for in HIC could be missed as risk factors for burn contracture formation. As most of the literature on burn contractures is from the HIC, current literature may present only part of the overall framework in which exploration of risk factors should be made. For example, lack of healthcare facilities, lack of physiotherapy, ineffective treatment, healing by secondary intention and lack of skin grafting (all amongst the most cited risk factors in LMIC literature) are not common problems in HIC and therefore are not recognised as contributing factors.

Other risk factors mentioned by LMIC sources but not by those of HIC are lack of education, poverty, ignorance, open wounds, lack of healthcare facility utilisation or failure to seek care, and lack of follow up. This also supports the former point; many of these are controlled for or, (due to more equitable and comprehensive healthcare), do not feature as risk factors in the HIC.

In conclusion, a wide range of putative risk factors for burn contracture have been identified from papers emanating from both HIC and LMIC.

2.10 SUMMARY OF LITERATURE REVIEW

This literature review has identified a wide range of evidence-based and putative risk factors for burn contracture formation, from a range of types of literature, study designs and populations. As this was not a systematic review and many different types of studies were included, individual papers were not

assessed using formal quality-assessment tool(s), but it was clear that most publications had flaws in at least one respect. The quality of papers from low-income settings was particularly low.

Most of the papers in this review report putative (i.e., assumed, or alleged) risk factors, some of which are supported by some evidence. In this challenging environment of multifactorial factors, it has been difficult to navigate an understanding of risk factors for burn contracture formation. In addition, many published studies have methodological flaws (often regarding the definition and measurement of risk and contracture) which undermine the strength or generalisability of the findings.

Many unanswered questions remain, due to a lack of adequately controlled prospective studies, and a lack of studies which examine the relative potency of risk factors, how the various risk factors interact, and which factors have the greatest impact on severity of contracture.

Because of the differences between HIC and LMIC environments, there may be some risk factors in common but there may also be some very different risks at play; for example, socioeconomic factors and healthcare system factors (i.e., the social determinants of health (Commission on Social Determinants of Health, 2008) may have a much greater impact on contracture risk in LMICs than in HICs. Due the very limited number of LMIC publications, it is also not known if there are other important risk factors for contracture in LMIC that have not yet been identified.

Table 2-23 summarises and categorises all the risk factors identified through this literature review. The risk factors identified in systematic reviews have been excluded from this table as those are captured in the other categories of original publications.

Table 2-23: Potential risk factors for burn contracture identified from literature review

	Risk Factor Studies	Descriptive Studies	Intervention Studies	Putative Reports	Totals
Patient Factors	14	8	0	14	36
Age	5			7	12
Gender	3	1		1	5
Place of residence		2			2
Lack of education		1		1	2
Lack of maternal education	1				1
Ethnicity	2				2
Poverty				1	1
Ignorance				1	1
Co-morbidities	1	1		1	3
Low pain threshold		1			1
Low adherence to treatment		1		2	3
Psychological problems		1			1
Social mockery	1				1
Lack of supportive nuclear family	1				1
Burn Injury Factors	27	11	0	49	87
Lack of first aid	1				1
Cause of burn	2	3		1	6
High TBSA	9	2		9	20
Number and location of CFU				1	1
Deep burns	4	2		12	18
Location of burn /scar	7	2		15	24
High pain				2	2
Thick/excessive scarring				4	4

Table 2-23: (continued)

	Risk Factor Studies	Descriptive Papers	Intervention Studies	Putative Reports	Totals
Burn Injury Factors (contd.)					
High fear / anxiety				1	1
Muscle weakness				1	1
Oedema				1	1
Neuropathy	1				1
Acute burn phase	1			1	2
Oedema				1	1
Amputation	1				1
Inhalation injury	1				1
Low pain tolerance		1			1
Lack of compliance		1			1
Medical/Surgical Treatment Factors	17	6	0	22	43
Delayed wound healing	2			13	15
Infection	1			1	2
Lack/delayed of skin grafting		3		8	11
Skin graft	1				1
Type of skin graft	1				1
High TBSA grafted	3	1			4
ITU stay	1				1
Number of surgical procedures	2				2
Long length of stay	2				2
Inadequate hospital stay		1			1
Complicated hospital stay		1			1
Number of surgical procedures	2				2
Number of surgical procedures	2				2

Table 2-23: (continued)

	Risk Factor Studies	Descriptive Papers	Intervention Studies	Putative Reports	Totals
Therapy Factors	0	8	10	107	125
Lack of/delayed physiotherapy		5		10	15
High rehab input/time		1			1
Lack of positioning				14	14
Lack of mobilisation				3	3
Prolonged immobilisation				4	4
Lack of functional activity				1	1
Lack of exercise			6	17	23
Lack of splinting		2	3	48	53
Lack of scar massage				2	2
Lack of pressure therapy			1	6	7
Lack of silicone gel				2	2
Health System Factors	2	6	0	14	22
Lack of healthcare facility utilisation	1			3	4
Lower level of healthcare visited	1				1
Lack of healthcare facilities				3	3
Treatment in rural healthcare		1			1
Delayed referral to specialist care		2			2
Incomplete/Ineffective treatment		3		7	10
Lack of follow up				1	1
GRAND TOTAL	60	39	10	206	315

The top five most frequently reported risk factors for all sources of literature, and with putative sources excluded is shown in Table 2-24.

Table 2-24: Frequency of report of risk factors from the review of literature

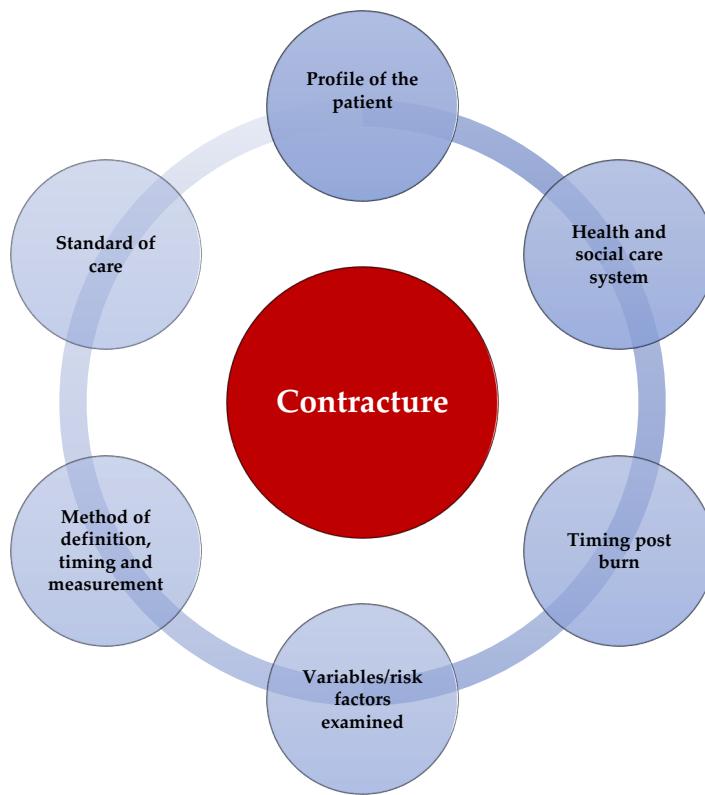
Rank of Report	All Sources	Frequency	All Sources Excluding Putative Reports	Frequency
1	Lack of Splinting	53	High TBSA	11
2	Location of Burn/Scar	24	Location of Burn/Scar	9
3	Lack of exercise	23	Lack of Exercise	6
4	High TBSA	20	Deep Burns	6
5	Deep burns	18	Age at time of burn	5
			Lack of Splinting	5
			Lack /Delayed physiotherapy	5
			Cause of burn	5

All five most reported risk factors from all sources, are also identified as such when risk factors from putative sources are excluded.

2.10.1 Key Issues Identified from Current Literature

Many confounding factors have made it difficult to identify real risk factors for burn contractures from the literature to date, especially those which may be most relevant in LMIC. The main areas of variability in published studies are summarised in Figure 2-2.

Figure 2-2: Key variations in published papers on contracture formation



Key issues identified in Figure 2-2 above are:

i) Standard of care

Different studies and clinical experience are influenced by varying standards of care, especially between HIC and LMIC settings. This has several implications:

- i) the general standard of burn care will affect the power of any intervention to ameliorate contracture development; many of the individual potential risk factors identified are affected by the standard of general burn care provided
- ii) different risk factors may be present or controlled for to varying degrees with different standards of care

The differences in standards of care are evident in the literature review, with far broader and more detailed treatment variables reported from HIC sources. Only one of the LMIC studies included physiotherapy treatment as a variable (Kim et al., 2012), whereas it was considered in detail by some HIC studies (Richard et al., 2017). Presumably this is not because therapy is considered unimportant (it is one of the most frequently reported putative factors from LMIC sources), but because it is not routinely available. Even if it is available, it is unlikely that the level and duration of follow-up and intensity would match that reported in the intervention studies from HICS.

ii) Health and social care system

The ease of access to general and specialist healthcare care is likely to affect the relative importance of several identified risk factors. In HIC settings where healthcare is either free, provided by insurance or affordable by the majority, family socioeconomic status may be less relevant to outcome. In LMIC settings, payments required for treatment may significantly constrain the ability of patients to access appropriate care at the optimal time.

iii) Profile of the burn patient

The characteristics of the study population may also impact final contracture rates, as many patient factors such as age will affect predisposition to contracture, as will burn injury factors such as TBSA and depth of burn. These factors may be very different in different studies and therefore may significantly alter the risk profile of the group under study, thus reducing generalisability of the findings and risks identified.

iv) Variables/risk factors examined

Different studies examine different risk factors. Risk factors are often not clearly defined, or are not standardised across studies, making comparisons of findings difficult.

v) Timing post burn

The duration of a study will have an impact not only on the risk factors which can be examined (such as rehabilitation follow-up interventions) but also on the reliable capture of contractures. Studies terminating at hospital discharge are unlikely to be able to be certain whether recorded loss of movement is due to contracture or other confounding factors.

vi) Methods of definition, timing, and measurement of contracture

As previously noted, inconsistent or absent definitions for contracture identification and measurement make comparisons of studies difficult if not impossible. The importance of the timing of contracture measurement has already been discussed.

vii) Quality of evidence

Although the quality of evidence was not formally assessed using a quality-assessment tool, as noted by the systematic reviews (Fergusson et al., 2007, Oosterwijk et al., 2017), the relatively poor quality of published evidence overall makes it very difficult to identify risk factors for contracture with any certainty. There are very few robust, well-controlled, prospective studies on risk factors for contracture development.

Notwithstanding all these issues, the literature review has identified a large number of potential risk factors. Factors reported to be protective against contracture formation (such as maternal education or splinting) have been referred to by the lack of the protective factor (i.e., lack of maternal education, lack of splinting).

2.10.2 Conclusion

This literature review has, for the first time, consolidated and categorised currently cited risk factors from all sources. From review of the current knowledge base and the apparent paucity of evidence from LMICs, it is apparent that further work is required to identify those risk factors which are specifically relevant to contracture development in LMICs.

2.11 RESEARCH QUESTION AND OBJECTIVES

From the findings of the literature review, the original research question, **“What are the risk factors for burn contracture formation in a low-income setting?”** has been confirmed to be worthy of further investigation.

The remainder of this thesis will endeavour to address this knowledge gap by addressing the following specific objectives.

1. Develop a framework of potential contracture risk factors suitable for primary data collection in a LMIC setting, including all factors identified from the literature review supplemented by those extracted from a small study of clinicians with burns experience in LMIC settings
2. Identify LMIC-appropriate outcome measures (i.e., contracture presence and severity) which allow objective stratification of study participants into standardised groups for comparison
3. Create a Data Collection Tool to gather data on the range of risk factors identified and document the standardised outcome data for subsequent analyses
4. Collect and analyse data from recruited LMIC burn survivors to identify risk factors affecting contracture formation and severity

3 METHODOLOGICAL OPTIONS: SELECTION AND RATIONALE

3.1 INTRODUCTION

This chapter reviews the methodological options and provides the rationale for how the research question, “**What are the risk factors for burn contracture formation in a low-income setting?**” is addressed within the scope of this PhD.

It is not possible to answer such a broad question in a single study. Not all LMICs are the same, and there may be great variation between different areas within any one country. There may also be systemic limitations in conducting clinical research in LMIC environments. As noted in the literature review, these include lack of patient databases, lack of timely patient access to effective healthcare and lack of routine follow-up of patients. HIC researchers conducting studies in LMIC contexts may also face cultural and language barriers and be unfamiliar with how the local healthcare system operates.

3.2 STUDY DESIGN

The study design selected was a mixed method, observational, cross-sectional analysis.

In an ideal situation, risk factors for contracture would be identified from a prospective long-term follow-up of acute burn patients, from whom comprehensive data on all potential risk factors would be collected, documented, and analysed at defined time-points during the natural history of contracture development. Contractures would also be defined and measured in a standardised way at each time-point. Matched controls at the same time-point post-burn but without contracture would also be evaluated.

Such a study would require considerable investment of time and resources, which was not feasible.

It was also anticipated that because LMIC patients usually only return to hospital for review if they perceive they have a problem (rather than for routine follow-up), it was unlikely that enough participants at risk of but without any contracture would be identified, therefore a sufficient control group for a study could not be guaranteed.

A cross-sectional study was chosen for the following reasons:

- Although a cross-sectional study may not be the most ideal study design and is more commonly used to measure prevalence (Wang & Cheng, 2020), a cross-sectional design can also be used to collect data on exposures and outcomes at a specific point in time. This allows comparison of outcomes with multiple exposures or risk factors for the purposes of exploring any associations between the two (Mann, 2013; Checkoway et al., 2007; Süt, 2014; Wang & Cheng, 2020) and would be consistent with the purpose of the study.
- Reliable secondary data, such as the extensive data sets utilised in the large American studies previously reviewed (Godleski et al., 2018; Goverman et al., 2017a; Richard et al., 2017; Schneider et al., 2006), are not usually available in any LMIC context. It was also thought unlikely that there would be any hospital databases which would cover all the potential risk factors and outcomes to be explored, so data collection directly from case notes and/or participants would be required. Additionally, the whole experience of the healthcare system from injury to the time of interview could be available through direct participant interview, which might expose important risk factors at a system level.

This data would be otherwise be difficult to extract from any other available sources of data.

- The use of a cross-sectional study design to explore contracture formation in LMICs is consistent with the literature, in which cross-sectional observational studies were the most frequently used study design.
- Lack of planned admissions for reconstructive surgeries and lack of routine follow-up reduces access to patients in a planned or predictable manner.
- Advance planning of any alternative study design was impossible due to the distance between the researcher and the study site and limited opportunities for communication with local staff, due to their high workloads and the language barrier. These factors underscored the need for a type of study which could capture data during a limited period without significant onsite planning; this would be more feasible with a cross-sectional study.
- Due to the higher incidence of burns in LMICs (Smolle et al., 2017), a large hospital environment should be able to provide considerable numbers of patients at any given point in time, which would facilitate a cross-sectional study.

It is recognised that this study design has several limitations. These include the difficulty of identifying a causal relationship between exposure and outcome, and that the exposure status may be a result of the outcome rather than its cause (Checkoway et al., 2007; Mann et al., 2003; Wang & Cheng, 2020). Additionally, a cross-sectional design within a healthcare setting may capture more 'healthy' participants as they have been able to attend, while those more severely affected by the exposure or outcome may be missed (Checkoway et al., 2007). However, these limitations were felt to be acceptable within the aims

of this research, which were exploratory and could generate hypotheses for future study, rather than expecting to capture a definitive causal relationship. The pragmatic advantages of the cross-sectional design were considered to outweigh the disadvantages in selection of study design. Therefore, it was decided that a cross-sectional study of burned patients over a limited fixed period with collection of relevant data primarily through interviews with participants, would be the most appropriate option available.

3.3 SITE SELECTION

A lower income setting with a high concentration of potential participants was required for this study. Considering the nature of a cross-sectional study, the best location to access burn patients effectively and efficiently would be a specialist burn hospital. A general hospital might not have sufficient burn patients and would be less likely to offer opportunities to investigate some treatment-related potential risk factors. A community setting would require much more planning and was likely to yield even fewer participant numbers.

Bangladesh has been classified by the World Bank as a Lower-Middle Income country since 2015 (World Bank, 2022), and is therefore an appropriate setting for the proposed study. The Department of Burn and Plastic Surgery of Dhaka Medical College Hospital (DMCH) in Bangladesh, is colloquially known as the ‘largest burn unit in the world’ (Bailey et al., 2019) and could be expected to have large numbers of suitable patients for study. Fortuitously, this researcher had considerable previous clinical experience at this hospital and had a good pre-existing relationship with hospital management which would facilitate the proposed research. Further justification for site selection is given in section 3.3.3.

3.3.1 The Health Care System in Bangladesh

Healthcare in Bangladesh is pluralistic, complex and provided at multiple levels including traditional healers, Government clinics/hospitals, private medical/surgical clinics and Non-Governmental Organisations (NGOs) (Ahmed et al., 2015). This rest of this section is based on the personal experience and observations of the author, discussion with local staff and observations made in Zaman's (2005) ethnography of a Bangladeshi teaching hospital.

The Government operates general clinics and some inpatient care at Upazila¹ level, but most inpatients are treated in District Hospitals or large tertiary Medical College hospitals associated with medical schools in the largest cities. While these hospitals are staffed by Government-paid employees (medical, nursing, allied health professions and administrative staff), staffing levels are very low compared to HIC, especially at Upazila and District level. Most staff are only expected to provide part-time Government-funded care; the rest of the time they are free to work in private practices, which is much more financially rewarding than the relatively low Government salaries paid. Consequently, the quality of care provided to patients is variable and can depend on the dedication and expertise of individual staff members. Even in Government hospitals, patients must pay for most medications, dressings, and any other treatments they may receive. NGOs sometimes assist with both the demands on the Government healthcare system and with the financial barriers to care faced by patients.

There are virtually no appointment systems in place except occasionally in private clinics; patients are expected to self-refer when they wish, which

¹ An Upazila is an administrative district at sub-district level

results in health professionals being unable to plan clinics or surgery, frequently insatiable demand, and a lack of routine follow-up.

For economic reasons and difficulties in accessing services in rural areas, many Bangladeshis still rely on village 'doctors' and traditional healers, who also demand payment, but at a much lower level. The efficacy of traditional medicine is a separate topic, but for many conditions, including severe burns, it is not likely to be comprehensive or fully effective.

For the small proportion of the population who can afford it, private healthcare is available in every town and city. There is very little effective medical regulation in Bangladesh, so the quality of care, even in the private sector, is variable and unaffordable for most patients. Expertise is dependent on clinicians' previous training, which may or may not include overseas training in HICs; consequently, knowledge of up-to-date burns care may be limited.

There are very few specialist tertiary units in the country, and most are housed in large Medical College Hospitals in the largest cities. In these units it is more likely that staff will have had specialist training and are keen to develop their own practices to high levels. However, the sheer numbers of patients seeking treatment (even tertiary units are expected to fulfil primary and secondary care functions) make the kind of regulated and standardised care seen in HICs impossible to achieve.

As there are no formal referral systems in place, many patients are unable to access even Government-provided specialist care because of lack of knowledge of how to do so, the very long distances to services and economic constraints. All this means that the quality and provision of acute burn care

varies greatly throughout Bangladesh; equitable access to burn care does not exist.

3.3.2 Description of Dhaka Medical College Hospital (DMCH)

DMCH is in the capital city of Bangladesh and is the largest Government hospital in the country. DMCH is a multi-specialist tertiary centre with 2900 beds. The Department of Burns and Plastic Surgery is located within DMCH, but in a separate building. The Department of Burns and Plastic Surgery of DMCH is referred to as DMCH Burn Unit or just DMCH throughout.

DMCH Burn Unit was established in 2004 with 50 beds; it was the first specialised burn service in Bangladesh. The Unit has now grown to an official capacity of 300 beds. Plans to increase the capacity to 500 beds and move to a newly built institution, The Sheikh Hassina National Institute of Burns and Plastic Surgery (SHNIBPS), were already underway when this study was planned; the service was relocated to SHNIBPS between the pilot and final studies.

Due to high demand, DMCH burn unit is well-known for accommodating more burn patients than its official bed capacity allows. Despite having 300 beds, on most days inpatient numbers reach 450-500. The extra capacity is met through utilisation of ward floor space and corridors for beds and mattresses.

Inpatient beds and outpatient clinics include some non-burn plastic surgery patients, but the primary case load (70%) in both areas is burns, either for acute burn treatment or post-burn reconstruction. Adults and children are generally treated in separate wards, as are male and female adult patients. There is a separate intensive care unit for adults and paediatrics. All these services are located within the same building.

In addition to the large numbers of inpatients, the same staff cohort manages a high-volume outpatient service. On average, 60-100 patients are seen daily in the outpatient department; most are acute or reconstructive burn cases, with some general plastic surgery cases.

This large caseload is managed by 40 doctors and 70 nurses. The only additional regular team members are 5 physiotherapists, who cover both in- and outpatient services.

In this setting, physical rehabilitation comprises only advice from doctors and some physiotherapy input. Although provision is limited, inpatient and outpatient physiotherapy is included in the Government-funded service. However, informal fees do exist and outpatient services require a small registration charge. Rehabilitative equipment such as splints, pressure garments and certain drugs must be paid for by the patient.

The only data kept at hospital level are the numbers of daily patients, gender and TBSA of the patients, causes of burn, mortality rate, and numbers/ types of operations. None of these data were collected electronically at the time of the study and were not readily available for scrutiny.

3.3.3 Rationale for site selection

DMCH was selected for the field study as its burn unit has a consistent and high volume of burn patients at all times of year (Bailey et al., 2019), which was also confirmed through communications with the hospital management. Acute burn and elective reconstructive patients (both inpatients and outpatients) attend within the same building.

The DMCH Senior Management Team were well-known to this researcher who had visited the hospital six times since 1998 (before the Burn Unit was

first established), working voluntarily as a clinician and educator for up to 6 weeks at a time. It was felt that there would be sufficient staff available to assist the researcher with the project, in particular with respect to overcoming the language barrier and addressing logistical challenges. A further important advantage was that the management of DMCH Burn Unit was interested in research which could help to reduce contracture formation. The Ministry of Health was also supportive of the project.

As it is a national centre of excellence for burns care, patients travel to DMCH Burn Unit for treatment from all over the country (Bailey et al., 2019). Patients who present at DMCH Burn Unit may have had delayed or even no previous treatment, or non-specialist care prior to arrival. Although there are standardized protocols of care at DMCH, the high numbers of patients arriving at different times of day, at different times post-burn and with variable abilities to pay for treatments, means that not all patients will have identical care. The diversity of this patient cohort, in terms of burn severity, socioeconomic factors and treatment strategies, produces some potential confounding factors but was thought to facilitate exploration of a broad range of potential risk factors.

It was considered important to conduct the study in a government hospital rather than in a private clinic, since the former represents the level and quality of care accessible by most of the population. However, since Government hospitals still require payments by patients for drugs and interventions, it is recognised that some patients may not have had financial access even for basic aspects of care. Additionally, patients' lack of funds can affect their length of stay in the Government hospital.

3.4 STUDY POPULATION

The study required a population of burn patients who were at risk of burn contracture.

3.4.1 Planned sample size

As this was an exploratory study to identify potential risk factors for contracture, there was no primary research question on which to base a power calculation. The purpose of the sample size calculation is therefore simply to ensure there is sufficient data to allow important risk factors to be detected. Given the large number of different risk factors and the non-parametric methods to be used, such calculations are inevitably very crude.

As a number of different risk factors, with varying distributions, had to be considered, and with no prior data, our sample size calculations were based on desired effect size. Estimations of Power for non-parametric methods are complex and so estimations based on parametric methods were used and were corrected upwards (by up to 15%) as recommended in the literature (Lehmann, 1998).

As most comparisons are performed with two or three independent groups, calculations for both t-tests and ANOVA were performed using the software package G*Power (Faul et al., 2007; Faul et al., 2009)

For large effect sizes and 80% power with t-tests and ANOVA, minimal (total) sample sizes of 42 and 66 respectively were required, increased up to 48 and 76 to allow for the use of non-parametric methods.

Taking account of the likely logistical constraints in data collection and the time available for the study, it was felt that a pragmatic target of 60 participants was both realistic and provided sufficient power for this exploratory study.

3.4.2 Identifying joints at risk of contracture

A burn injury does not inevitably incur a risk of contracture, so criteria were required to identify joints at risk of contracture.

Most studies in the literature did not consistently define or specify what constituted a joint at risk of contracture. Studies which did refer to 'joints at risk' defined them in one of the following ways:

- i. a burn over or adjacent to a joint surface (Dobbs & Curreri, 1972)
- ii. the involvement of cutaneous functional units (CFU), which are pre-determined areas of skin required for full movement of that specific joint (Richard et al., 2009; Parry et al., 2019)
- iii. by dividing the area between 2 adjacent joints (e.g., wrist and elbow) into thirds, and if the scarring was in the nearest third to the joint then this would be considered a joint at risk (Schouten et al., 2019).

The CFU system of defining joints at risk in ii) above was considered for use and communication was initiated with the authors of the relevant publication (Parry et al., 2019), but a software programme was required to determine the CFUs; this was not feasible or practical in the low resource setting of the planned study, especially when other adequate options for measurement were available.

The article by Schouten et al. (2019) was the first and only study to use the 'thirds' method of defining joints at risk, the authors did not report any rationale for, or validation of, their method. This method was felt to be overly generous in terms of the distance between visible scarring and the surface of the joint and does not necessarily reflect how joints at risk are identified in clinical practice; this method could potentially inflate numbers of joints at risk, under-report contracture rates and reduce ability to identify risk factors. In

the same study by Schouten et al. (2019), joints classified as ‘at risk’ which had a burn directly over the joint, as compared to burns adjacent to the joint, had considerably higher contracture rates.

Therefore, the definition of joints at risk used by Dobbs & Curreri (1972) (i.e., any deep burn over or immediately adjacent to a [major] joint) was preferred.

However, none of the published studies reviewed specifically defined the identification of a joint at risk after the acute phase, when a visible burn wound was no longer present. Therefore, the definition of a joint at risk for the reconstructive group in the present study would have to rely only on the visible scarring, which has been assumed to correlate with the presence of a deep burn.

For the purposes of the present study, a joint at risk was therefore defined as ‘observable significant scarring which met or crossed a joint line’.

3.4.3 Selection of joints for study

Contractures can occur in many anatomical locations, including major and minor joints and some other body areas such as eyes, mouth, nose, breast and perineum. Some joints are more complex to measure than others, and some facial features have less established measurement protocols than joints and are more difficult to quantify. Hands and toes have multiple small joints, each of which would require individual measurement and evaluation if included.

As time with each study participant was likely to be limited, it was necessary to restrict the number of joints included in this study, so a decision was made to include only major joints (neck, shoulder, elbow, wrist, hip, knee and ankle). This selection was also consistent with the majority of studies identified from the literature review (Schneider et al., 2006; Schouten et al., 2019).

It was determined that only patients who had at least one major joint at risk of contracture would be included, but there would be no limit on the number of joints per participant included. Taking account of possible bilateral limb injuries, the maximum number of included joints per participant would therefore be thirteen.

It was decided that any contracted joint which had undergone previous reconstruction should not be included. This was because it would be difficult to separate the risk factors for the initial contracture from those which resulted in the recurrence, and it was not likely that the recurrent contracture would be of the same severity as the original one. It was recognised that this could potentially artificially reduce the number of contractures documented in some patients.

3.4.4 Time of assessment after burn injury

The optimal time post-burn at which to conduct the study required consideration, both for the capture of risk factors and the measurement of contractures. Contractures are not likely to be present in the initial stages of a burn injury as scar tissue has not yet developed, even if the patient is at high risk of contracture. Equally, limited measured range of movement (ROM) in the early phase may be affected by confounding factors such as oedema, dressings, and pain rather than burn contracture. Inclusion of participants too soon post-injury could therefore under or over-report contracture and confound contracture measurement.

In addition, capture of risk factors in the earlier phases of a burn injury would truncate the number of risk factors examinable, as the influence of certain potential risk factors such as follow-up rehabilitation input would have not yet had effect.

Contracture presence and severity may also increase or decrease according to the time post-burn (Schouten et al., 2019 and 2021). Depending on the time of measurement, a joint that had no contracture initially could subsequently develop one and vice versa; equally a joint that had a mild contracture could progress to a severe contracture and vice versa.

For the above reasons consideration was given to only including participants with a burn injury more than 2 years old, as by this stage any contracture would have stabilised. However, since a very prolonged time since injury would likely negatively affect participant recall, it was determined that any late-stage reconstructive group participants should be >2 years but <10 years from initial burn injury.

Despite the need to allow enough time for contractures to stabilise fully, including participants earlier in their recovery journey also has advantages. Recall of factors surrounding the actual burn injury and initial treatment is likely to be better in patients who are still in the acute phase of healing. It was also thought that more detailed medical documentation would be available for this group. The researcher would also be able to observe some potential risk factors directly, such as the location and depth of burn, whether a splint was effective and whether a patient was adhering to treatments given. Although availability of acute participants at DMCH was guaranteed due to the high volumes of acute burn patients, the number of elective reconstructive participants was relatively unknown and less reliable. Therefore, it was felt that a combination of acute and reconstructive patients would enable study of risk factors across a broad time frame of the recovery journey, and the advantages and disadvantages of early and later examination of risk factors could be balanced. Consequently, two groups were defined:

- 1) an 'acute' group of patients admitted for burn injury, who still had acute burn wounds at the time of interview and were inpatients at the time of study.
- 2) A 'reconstructive' group comprised of inpatients or outpatients whose acute burns had healed but who had a burn contracture requiring surgical release at the time of interview.

Reconstructive participants should be at least 2 years post-injury when their contractures were most likely to be 'fixed', but the ideal time for study of the acute group was less certain. It would be important not to evaluate patients before any sign of contracture was likely, as this could diminish or prevent identification of potential risk factors. A common time-point used for measurement of contracture in the literature is hospital discharge (Godleski et al., 2018; Goverman et al., 2017; Schneider et al., 2006), usually reported as being around 21 days from injury, when a patient is medically fit. However, in LMIC settings, many other factors (including costs, lack of social support, prolonged distance from family and economic effects of not working) affect discharge timing. Discharge times are therefore likely to be very different in LMIC and HIC settings. Additionally, in LMIC settings, discharge is frequently spontaneous and immediate rather than scheduled, making it difficult to plan the timing of pre-discharge contracture evaluation.

It was therefore decided to evaluate acute inpatients based on the earliest time at which a contracture would likely be first identifiable, which in current clinical practice is generally considered to be around 4 weeks; any patient with an injury < 4 weeks old would not be included in the study.

3.4.5 Age of participants

Although young age at the time of burn is cited as a risk factor for burn contracture and therefore worthy of exploration, it could also be viewed as a

confounder to other risk factors. The presence and severity of a contracture because of a childhood burn injury may be considerably impacted by the growth of the child rather than generic risk factors applicable to all burn patients. Therefore, it was decided that ideally only adult patients (defined as ≥ 18 years) would be included in the study. Similarly, in the reconstructive group, ideally only participants with a contracture following a burn injury which had occurred in adulthood would be recruited.

3.4.6 Cause of burn

It was determined that any cause of burn would be included in the study.

3.5 RISK FACTORS

A decision was required on which risk factors to examine within the study. The literature review generated many potential risk factors, but the evidence did not confirm which were most important and most publications reported risks identified from a high-income context. It was therefore determined that the present study should be exploratory and consider a wide selection of risk factors, to provide an initial foundation on which further LMIC research could be built.

Due to lower numbers of publications from LMICs, it was decided to augment the risk factors drawn from the literature with a survey of burn care clinicians currently working in LMIC settings.

The process of determining risk factors for investigation in the final study is fully described in the next chapter.

3.6 METHOD OF DATA COLLECTION

Data for cross-sectional studies are generally collected through self-administered surveys/questionnaires or through interviews. The method of

data collection deemed most practical for this study was a face-to-face semi-structured interview with eligible participants. Variable literacy rates and the difficulty of capturing accurate information on such a broad range of medically orientated risk factors also favoured an interview process, rather than a survey or self-completed questionnaire. Data collection directly from the participant would also enable measurement of any burn contracture(s) during the same encounter. Interpretation services would be required to facilitate interviews with non-English-speaking participants.

A purpose-designed interview guide was required to ensure efficient extraction of the selected information on the presence/absence and extent of risk factors contributing to burn contracture formation in the study population. The questions would need to be understandable by non-clinicians, including interpreters, and by potentially uneducated or poorly educated participants.

Due to the differing times of evaluation and variable ranges of risk factors relevant to the acute and reconstructive groups, different interview guides would be required for each group. The development of the interview guides is described fully in the next chapter.

3.7 TYPE OF DATA

Although exploratory studies are often qualitative in nature, risk factors are more commonly identified through quantitative methods. Existing literature on risk factors for burn contracture is mainly quantitative in nature. There is no qualitative measurement system for contractures, therefore contracture measurement required a quantitative approach. A few interview questions could provide some qualitative data, mainly regarding participants' opinions on what they believed were risk or protective factors for burn contracture

formation. Questions to reconstructive participants could also be more qualitative than those for acute participants, as it was anticipated that the former would have a more comprehensive story to tell from injury to point of interview. A mixed method study design was therefore deemed most appropriate for this study.

3.8 THE LANGUAGE BARRIER

Unfortunately, this researcher was unable to speak Bangla and it was anticipated that most participants would not be able to speak English uniformly or fluently. Therefore, the study would require involvement of an interpreter to ensure participants were informed about, understood, and consented to the study and could understand and respond to the interview questions. The researcher would also require interpretation of patient responses. Despite the potential limitations of using third-party interpreters, it was recognised that interpretation would be essential.

3.9 STUDY OUTCOMES

The outcome measure against which potential risk factors would be analysed would be contracture and would include both the presence/absence of contracture and the severity of any contractures present.

In clinical research, the outcome used must be clearly defined and have a valid and reliable measurement protocol. This study therefore required both a definition of contracture and a reproducible measure of contracture severity. The definition and severity of contracture would need to be operationalised through the creation of a robust measurement protocol (Kimberlin & Winterstein, 2008; Milne, 2007; SAGE, 2017).

3.9.1 Defining Contracture

The literature did not offer any contracture measurement technique which was comprehensive or specific enough for this study; the lack of standardised contracture measurement is well-reported. The first publication to highlight the lack of any standardised measure for contracture was a survey of 121 American burn therapists which included a literature review of available methods of contracture measurement (Parry et al., 2010). The conclusion of that study was “The choice of methods and tools used to measure burn contracture are varied and inconsistent among both clinicians and researchers. Currently there is no standard within the burn care community for measuring for contracture” (Parry et al., 2010, p.900).

Since that time, there have been increasing calls for a standardised measure of contracture (Cai et al., 2016; Ehanire et al., 2013; Fanstone 2019 and 2021; Oosterwijk et al., 2017; Parry et al., 2019; Schouten et al., 2019), and as captured by Oosterwijk et al. (2017) “a worldwide accepted definition and operationalisation of contractures is required” (p. 47).

Although general concepts for contracture definition, measurement and outcome were available from the literature, further consideration was required to develop an operational definition and a measurement protocol suitable for the present study.

As noted in the literature review, the term ‘contracture’ is not defined at all in many publications. In those papers where contracture is defined, often simple definitions are used such as “contractures are defined as an inability to perform full range of a joint” (Goverman et al., 2017, p. 329). Available definitions of contractures focus primarily on the concept of loss of movement at a joint; the assumed or perceived reason for this loss is often also stated e.g., from scar tissue. Some definitions include the impact of the contracture, in

which case the focus is on the impact of loss of function such as "Scar contractures impair the range of motion (ROM) of joints and thus may limit performing activities of daily living." (Oosterwijk et al., 201, p. 42).

The definition of contracture considered by this researcher to be the most comprehensive available in the literature and the most feasible for use in the present study was: "an impairment caused by skin with pathological scar tissue of insufficient extensibility and length, resulting in a loss of motion, or tissue alignment of an associated joint or anatomical structure" (Richard et al., 2009, p. 265).

A detailed operational definition of contracture which eliminates ambiguity is vital to collect consistent data. The selected definition highlights the importance of a loss of movement at the joint but does not include any guide or instruction for actual measurement of contracture. Some additional detail is required, such as how loss of movement can be quantified, and what type(s) of movement(s) should be considered. Some studies reporting measurement of contractures do include some practical details but there is no gold standard or consensus.

3.9.2 Options for classifying contracture severity

Various methods for measuring contractures in burns patients have been described. The main features, advantages, and disadvantages of each are discussed below.

3.9.2.1 Subjective visual assessment ('eyeball measurement')

The clinical experience of this researcher along with the literature confirms that often contractures are not measured objectively - rather a subjective assessment is used, or what is termed 'eyeball' measurement (Edgar et al., 2010). The 'eyeball' method refers to the assessor's visual estimation of the

available range of movement (ROM) or loss of ROM, often reported in degrees, but without the use of a goniometer. This is the only method which this researcher has seen used in LMIC settings; it requires no technology or special arrangements. However, subjective contracture measurement is not robust enough for the present study, which requires a more objective and reproducible determination of contracture severity as an outcome measure.

3.9.2.2 Goniometer measurement

Other than subjective assessment, the most common and established method of contracture measurement utilises a goniometer, (Oosterwijk et al., 2019; Parry et al., 2019; Parry et al., 2010) which allows ROM (or loss of ROM) to be reported accurately and objectively in degrees. This involves the placement of a goniometer at the joint. The arms of the goniometer are placed over the axes of the joint to follow the proximal and distal limbs/parts and the angle of the goniometer is altered to capture the degrees of movement available at that joint.

Within the non-burn population, goniometry has been well-researched and found to be a valid, reliable, and responsive measure of ROM through rigorous testing (Low, 1976; McWhirk & Glanzman, 2006; Norkin & White, 2016).

However, it is important to assess clinometric properties of a measure in different populations (The et al., 2013). Interestingly, despite the widespread use of goniometry in burn care and the frequent assertion that goniometer measurement is validated in burn patients, the evidence for such validation is minimal. There is only one article (Edgar et al., 2009) which is routinely cited to support the validity of goniometry measurements in the burn population. This study investigated the intra- and inter-rater reliability of goniometry in four therapists and 45 patients. The study reported excellent intra- and inter-

rater reliability (ICC>.99 and ICC>.94 respectively) in burns patients studied (Edgar et al., 2009).

Although goniometry remains the most established and commonly accepted objective measure of contracture within clinical practice, there have been some recent calls to move away from goniometry in its current form (Oosterwijk et al., 2019; Parry et al., 2019). The two main arguments for change are i) a need for functional measurement of contracture rather than simply reporting loss of ROM in degrees and ii) interest in the use of cutaneous functional units (CFUs) as the basis for measurement of contractures.

3.9.2.3 Contracture measurement by function

Oosterwijk et al. (2019) are proponents of the need for a functional method of contracture measurement. Oosterwijk et al. (2009) recommend “International consensus is required on disregarding normative ROM based operationalisations of joint flexibility problems and adopting a new function-related operationalisation” (p.7), her opinion is supported by others (Ehanire et al., 2013; Parry et al., 2019). The rationale for a functional method is that the essential problem with a contracture is the resultant loss of function caused by loss of ROM. “However, the significance of scar contractures lies in their limiting effects on function, including the performance of daily tasks. This means that the use of normal ROM is only relevant if it is approximate to the ROM that is necessary for ADL.” (Oosterwijk et al., 2019, p. 2).

The impact of a contracture on function will vary in different joints due to the function(s) dependent on that joint and the extent of ROM required to execute the function(s). The functional approach to contracture measurement was rejected for the purposes of this study for the following reasons:

- i. Although comprehensive work has started on the development of a functional measure for contracture (Oosterwijk et al., 2018; Schouten et al., 2021), accepted measures were not available at the time of the present study. Furthermore, the functional ranges offered represent functional activities relevant to HIC participants and are not necessarily LMIC functional requirements.
- ii. The present study focuses on the impact of patient and burn characteristics, treatments, environmental and health system factors on the formation of contractures, rather than the impact of a contracture on quality of life. Therefore, a simple metric of movement lost as an indicator of the presence and severity of a contracture would suffice for the present study.

3.9.2.4 Cutaneous functional units

Richard et al. (2009) identified the areas of skin recruited during excursion of a joint through its full range and demonstrated that the skin involved in a joint movement is not just that adjacent to the joint but can include skin a considerable distance from the joint crease. Therefore, the position in which the proximal and distal joints are placed for joint measurement could affect the range of movement available at the measured joint (Richard et al., 1994).

Currently all goniometry protocols are based on arthrokinematics models; starting position is based on the reduction of influence of muscles crossing two joints. In burns, the limitation to joint movement is caused primarily by lack of skin excursion, not muscle length. For these reasons, Parry et al. (2019) proposed a cutaneokinematic rather than an arthrokinematic approach to measurement of movement loss in burns patients. The essential difference between the two approaches is that the cutaneokinematic method positions the distal joints in a ‘taut’ position to measure a joint whereas the

arthrokinematics method places the distal joint in a ‘slack’ position. Parry et al. (2019) concludes “The currently used standard goniometric measurement protocols may be over-reporting ROM outcome and under-representing the motion problems in burn survivors. The new revised protocol is therefore recommended for clinical use in research when measuring motion in an individual with scarring” (p.24).

The CFU method of measurement was considered for use in the present study but was rejected because a) even the simple equipment required to achieve the testing positions (foam wedges) could not be used in this study due to lack of availability and potential infection control issues and b) for an exploratory study in a challenging setting it was considered preferable to use methods familiar to the researcher and currently well-used in the literature to date.

The calls for a functional definition and measurement of contracture and the use of CFUs originate from HIC settings, and to date have not been supported by LMIC sources.

3.9.2.5 *Surgical scales*

There are several other classifications or measures of contracture utilised in surgical papers, mainly to assess the type and extent of surgery required and to measure improvement from surgery. The classifications tend to use grades such as I-IV to represent contracture severity, are joint-specific and based on the extent and location of tissue affected by scarring. Examples include shoulder classifications I-IV by Kurtzman and Stern (1990) and neck classifications I-V by Hyakusoku et al. (2010). The main disadvantages of these classifications are that they require specific evaluation of different aspects of every joint and are potentially subjective. A systematic review of the effectiveness of different surgical techniques for burn contracture stated that no conclusions could be drawn due to the low quality of studies, which in

large part was due to insufficient methods to measure or classify contracture (Stekelenburg et al., 2015).

Although surgical classifications were considered for use in the present study, they were not deemed appropriate for the following reasons: a) the surgical scales were often very subjective, b) invariably the measures were joint specific; no single measure was applicable to all major joints, c) they were often based on specific surgical procedures required; as a non-surgeon, this researcher was not confident in using them.

3.9.2.6 Quality of life measures of contracture severity

Measures of quality of life (QoL) and patient-reported outcomes used in burn care were also considered for use in determining the severity of contracture as an outcome measure for the present study. Unlike scar assessment tools (Fearmonti et al., 2017; Van de Kar et al., 2005), there are no contracture measurements which are based on or include patient input. Surprisingly, QoL measures do not include any contracture measurement scale, although functional or activities of daily living (ADLs) measures are often included and may reflect ROM lost. However, as reported by Elanire et al. (2013) in a systematic review of burn-related Quality of Life (QoL) measures, none of the QoL scales reviewed included function as an isolated construct, therefore scores for function were not separately identifiable. Elanire et al. (2013) concluded “There is no psychometrically valid self-reported scale specifically developed to comprehensively evaluate ADL as an independent measure of physical functionality and contracture in burn patients” (p. 528).

As with functional measures, QoL measures are more indicative of the impact of contracture on the patient. While this is important, it is not the focus of the present research, which requires an objective determination of contracture severity. QoL measures were therefore rejected for this study.

3.9.3 Contracture Measurement in LMIC Settings

In addition to validity, reliability and responsiveness, an outcome measure should also demonstrate cross-cultural validity (De Vet et al., 2011). An outcome measure which is validated in one population may require additional validation for different population groups (The et al., 2013). None of the measures used in burn care and referenced so far in this chapter, are known to have been assessed for clinometric properties in the LMIC population. The lack of outcome measures for burn scar patients is noted by Cai et al. (2016) “Given the particularly high incidence of burn injuries in LMIC, outcome tools for burn scar patients must bear in mind the resource limitations of its most likely subjects” (p. 897) and “burn contracture outcome studies that are set in LMIC countries often use highly subjective metrics that are difficult to compare across raters, such as very good, good satisfactory and poor” (p. 900).

None of the studies from LMICs offered any specific definition or measurement of contractures; the most common method of describing contractures in LMIC studies was a clinically determined need for contracture release +/- photographs of contractures. One study from a LMIC context (Forjuoh et al., 1996) used the International Classification of Impairments, Disabilities and Handicaps (ICIDH) to describe outcomes. The terms used were ‘physical impairment’ (“any loss or temporary/permanent abnormality of an anatomical structure or function resulting from the burn injury at the moment the initial treatment phase ended”) and ‘disability’ (“any limitation in the performance of an activity considered normal for the child in the context of his or her sociocultural and physical environment resulting from burn related physical impairment”) (World Health Organisation 1980, cited in Forjouh et al., 1996).

These definitions were not adopted for the present study because it is possible to have a burn contracture which does not cause physical impairment or disability as defined by ICIDH. Conversely, even patients without contracture could fit the definition of 'disability' if their scar prevented sociocultural participation for aesthetic reasons.

Only three publications reported measures of burn contractures in LMIC settings (Cai et al., 2016; Cai et al., 2017; Garcia et al., 2016). Of note, all these publications are international collaborations with HIC first authors. Each article proposes a new tool for assessment of burn contracture in reconstructive patients; two have a focus on quality of life and are the first publications to include any patient-reported components of contracture measurement (Cai et al., 2016; Cai et al., 2017). The third used the proposed contracture assessments for the purposes of predicting which patients would benefit most from reconstructive surgery in order to prioritise surgical resources (Garcia et al., 2016).

These methods were not used in this study for the following reasons because:

- a) they were developed to measure post-burn reconstruction and this study does not include reconstructed joints
- b) they were more time-consuming to use than goniometry
- c) they would provide more information than required for this study
- d) their focus is on quality-of-life measurement
- e) they were developed for the hand, upper limb, and neck only.

This study required a simple measurement protocol that could be used for each major joint.

3.9.4 Summary and Selection of Contracture Measurement Tool

As goniometry is currently the most widely accepted and established method of contracture measurement in clinical practice and was feasible in the

proposed setting, it was the preferred measurement tool for the present study. Despite its lack of regular use in LMIC, this researcher has extensive experience with goniometry, and it requires no special technology. There is no accepted specification of the 'best' goniometer; very few studies state which goniometer has been used and there is no consensus or gold standard. For the purposes of this study, an 8-inch plastic goniometer manufactured by 66fit™ was selected because it was of low price, easily accessible and calibrated to the International Standards of Measurement (ISOM) system.

3.9.5 Creating a Protocol for Contracture Measurement Using Goniometry

3.9.5.1 Key issues

The use of goniometry must be standardised to develop consistent and reproducible measurements. If any protocol for goniometry was found in the literature, only minimal detail was provided such as "The patients passive ROM was measured with a lateral goniometer according to the standardized protocols of Norkin and White" (Schouten et al., 2019, p. 784). As the full method was not given, it is not possible to know how closely the study adhered to the protocol referenced.

Important considerations when constructing a protocol for goniometry measurement include the following:

- a) Placement of the goniometer over the joint should be standardised. The Norkin and White (2016) protocol is the most cited system used in burn studies (Edgar et al., 2009; Parry et al., 2010; Parry et al., 2019;) and was considered acceptable for this study.
- b) Depending on the context and reliability of the tool used, having more than one assessor taking measurements might be expected to increase the validity and reliability of results. Interestingly, no studies found in

the literature review reported the number or experience of assessors involved in measuring contractures. Only one article reported that the assessor was blinded to the intervention used in the study (Deng et al., 2016). As goniometry has been found to have good inter- and intra-rater reliability (Edgar et al., 2009) it was decided that measurements would be made by the researcher herself and the local physiotherapist.

- c) It is well established that the position of the patient as well as that of the extremity or limb segment is a fundamental and critical factor for the reliability of goniometry in measuring joint ROM (Edgar et al., 2009; Rothstein et al., 1983; Sabari et al., 1998; Watkins et al., 1991). The Norkin and White protocol (2016) describes how the patient should be positioned, supporting its selection for this study.
- d) Movements used to demonstrate the ROM at any joint can be passive or active. Active movement is executed by the patient, and passive by the assessor. Within the burns clinical community there is no consensus on the most appropriate type of movement which should be measured. Some studies advocate passive movement as being a better indicator of scar pliability (Richard & Santos-Lozada, 2017) and report it to be less affected by patient factors such as weakness or pain. Other studies use active movement because it is more likely to represent the functional range available (Edgar et al., 2009). In the literature, there appears to be a slight preference towards using passive ROM. For the present study, the researcher decided to measure both passive and active movement.

3.9.5.2 *Movements measured*

Movement itself can improve or completely overcome a contracture; joint measurement on the first movement may be different from measurement on the fifth movement. It is therefore important to standardise the number of movements over which joint measurements are taken. There is no standard in

the literature and the number of movements on which measurement is made is not given. A decision was made to measure 3 passive and 3 active movements in each plane of movement measured for every included joint. This would allow report of a mean measurement, give opportunity to explore any differences in results between active and passive ROM and decrease the likelihood of confounders to limited range, such as initial resistance to movement from the patient.

The decision had already been made to include only major joints, but there are several different planes of movement available at each joint. It was recognised that the time available to study each participant would not allow measurements of every plane of movement in every joint at risk. In addition, there are certain movements at each joint that are more likely to be affected by contracture (Table 3-1). Even if there is a significant contracture in one plane, there are other movements at the joint that may not be limited. A pragmatic decision was made to measure only selected movements at each major joint at risk (Table 3-1). Other authors have used the joint and movement selections made for this study (Goverman et al., 2017a and b; Oosterwijk et al., 2019). For joints where more than one plane of movement would be measured (i.e., all joints, other than the neck) it was decided that the movement with the most limited range would be used to represent that joint in terms of contracture severity. This method of defining contracture severity at joints was used by Schneider et al. (2006) and Goverman et al. (2017a and b).

Table 3-1 shows the movements available at each major joint, those which are normally most affected by contracture, and those which were selected for measurement in the present study. The same movement planes were measured for both acute and reconstructive participants.

Table 3-1: Joint planes of movement most affected by contracture

Joint	Type of Joint	Movements Available	Movements Commonly Affected by Contracture	Movements Selected for Measurement
Neck	Condyloid	Flexion		
		Extension	x	x
		Lateral side flexion		
	Pivot	Rotation		
Shoulder	Ball and socket	Flexion	x	x
		Extension		
		Abduction	x	x
		Adduction		
		Circumduction		
Elbow	Hinge	Flexion		
		Extension	x	x
		Supination		
		Pronation		
Wrist	Condyloid	Flexion	x	x
		Extension	x	x
		Ulnar deviation		
		Radial deviation		
		Circumduction		
Hip	Ball and socket	Flexion		
		Extension	x	x
		Abduction	x	x
		Adduction		
		External rotation		
		Internal rotation		
Knee	Hinge	Flexion		x
		Extension	x	x
Ankle	Hinge	Dorsiflexion	x	x
		Plantar flexion	x	x
		Eversion		
		Inversion		
		Circumduction		

3.9.5.3 Stratifying contracture severity

In addition to judging a contracture to be present or absent, quantification of its severity provides further information which may aid identification of important risk factors. A loss of as little as 5 degrees movement will classify a joint as being contracted but does not differentiate that joint from one which has lost most of its movement.

Measurement by goniometry does provide raw data on contracture severity, captured by degrees of movement lost as a continuous variable. However, other methods of contracture classification based on categorical data were also considered for use in this study. None of the articles from low-income countries identified from the literature review measured contracture severity, although photographs included in some of the publications often illustrated very severe contractures. Three papers, one from China and two from Iran did quantify contracture severity; Deng et al. (2016) used the Schneider et al. (2006) scale (Table 3-2) and Karimi et al. (2013) measured ROM in degrees with a goniometer, then developed categories for mild, moderate, and severe contractures based on three arbitrary cut-off points. Categories given for the wrist were consistent with the Schneider scale, although not referenced. The other joints included in the study (knee, elbow, ankle) appeared to have arbitrary cut-off points to differentiate between severity categories.

HIC studies which reported a severity scale or other categorisation of contracture severity are summarised in Table 3-2.

Table 3-2: Contracture severity scales described in HIC literature

Reference	Severity Categories	Description
Dobbs & Curreri, 1972	Acceptable	ROM limited in only the final arc of motion; ROM is > 50% of normal ROM
	Functional	Approximately 50% of normal ROM, patient can do activities of daily living
	Severe	ROM < 50% of normal, reconstructive surgery is required for the joint to become functionally useful
Huang et al. 1978	No contracture	No limitation of ROM
	Mild	< 25% ROM lost
	Moderate	"Loss of ROM is about 50%"
	Severe	< 25% normal ROM
Niedzielski & Chapman, 2015	Within functional limits /mild/ moderate / severe/very severe	Based on degrees of movement lost for each movement of upper limb joints only
Schneider et al. 2006, Goverman et al. 2017a and b	Mild	< 1/3 ROM lost
	Moderate	Between 1/3 and 2/3 ROM lost
	Severe	> 2/3 ROM lost
Godleski et al. 2018	Absolute loss	Degrees of ROM absent from normal
	Percentage loss	Absolute loss shown as percentage of full normal ROM

Most of the severity categorisations above are subjective, were initiated by the authors, and have not been validated or tested for reproducibility. This absence of accepted contracture severity scales in the literature is consistent with clinical practice. In a survey of 121 burn therapists, only 6% used any severity scale (Parry et al., 2010); 4 used the modified Vancouver scar scale (which is a scar assessment scale, and does not measure contracture), 1 used a surgical classification, 1 used a locally developed classification which was unpublished, and 1 respondent's scale was not described.

In the face of such limited options, a decision was made to utilise both the Schneider et al. (2006) and Godleski et al. (2018) methods of severity classification in the present study. Both could be determined from the raw data

captured by goniometer measurement. The Schneider et al., (2006) method was selected as it was simple and most frequently cited. The Godleski (2018) method, based on a proportional representation of available to normal ROM at each joint provided a continuous variable output and would offer an alternative scale of severity. Both methods were slightly adapted for this study:

- i) the Schneider et al. (2006) article appeared to include some joints with full ROM in the mild contracture category; it is assumed that this was a print error. For the present study, any joint achieving full ROM would be classified as 'no contracture'.
- ii) the Godleski et al. (2018) paper defined full ROM in relation to an arc of movement, e.g., the full ROM of a shoulder included both abduction and adduction. As not all movements within a single arc of movement were to be included in this study, the measured ROM (and relevant normal ROM) for each included joint was taken from the neutral position rather than the extremes of the arc.

3.9.5.4 *Expected normal ROM*

In order to identify any loss of ROM, it is also necessary to have a baseline for expected full ROM for every joint, with which to compare the actual measured ROM. There are various classifications detailing normal ranges of movement for each movement axis at every joint (American Association for Orthopaedics Surgery, BMS National Database Data Dictionary). American studies presented in the literature review also detail the expected range of movement at each joint (Schneider et al., 2006; Goverman et al., 2017; Godleski et al., 2018). It was decided to use the figures for normal ROM given by Goverman et al. (2017a) as the expected normal range of movement for the present study; these are detailed in the Methods chapter. The normal ranges used in these studies

were detailed in the Model System for Burn Injury Rehabilitation National Database Data Dictionary. These baseline data were also used for calculation of percentage loss of ROM and contracture severity categories.

3.9.6 Levels of analyses: Person vs joint

Some risk factors consistently affect every joint at risk within a single participant i.e., exposure to the risk factor is the same at each joint at risk. Examples include demographic and socioeconomical factors such as age or household income, or certain burn/medical/treatment factors, such as TBSA, comorbidities, and length of hospital stay. In contrast, some risk factors (particularly some treatment factors), are more relevant to individual joints. Examples include the presence or absence of skin grafts, splints or pressure garments at a specific joint. Consequently, different joints in the same participant may have different exposures to these risk factors. Therefore, exploration of these risk factors was considered more appropriate at the individual joint. Accordingly, for the purposes of this study, it was determined that two levels of analyses would be undertaken - 'person level analyses' and 'joint analyses'. Person level analyses measured the impact of a risk factor on the 'whole person'. The 'joint analyses' investigated the impact of risk factors at the individual joint level. This required definition of two levels of outcomes that pertained both to the whole person and to any individual joint (detailed in Chapter 5, section 5.5.3). The results for person and joint analyses are also presented separately in Chapters 6 and 7 respectively.

3.9.7 Summary

After consideration of all options, it was determined that this study should be a cross-sectional, mixed-method exploration of potential risk factors, based on semi-structured interviews with burn survivors with at least one major joint at risk of contracture. Participants would include both those in the acute phase

of healing and those at a later stage in their recovery. A semi-structured interview guide for each group would be required to extract data on potential risk factors identified from the literature and views of practising LMIC clinicians. The outcome measures of contracture presence and severity would be evaluated through a standardised protocol of goniometer measurement of selected movements at included joints compared with accepted normal reference values.

The development processes for the interview guides, measurement protocol and data collection tool (DCT) are described in full in the following chapter.

4 DEVELOPMENT OF DATA COLLECTION TOOL

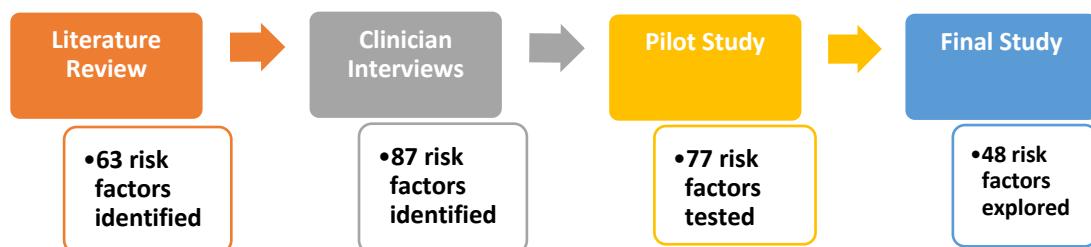
4.1 INTRODUCTION

The development of the interview guide to collect data on risk factors in the study population is reported in this chapter; the process is summarised in Figure 4-1. The literature review and interviews with burn care professionals provided the potential risk factors for examination.

Due to financial and logistical constraints, it was not possible to conduct more than two field visits (the pilot and the final study); consequently, LMIC participant involvement was not feasible prior to the pilot study. Burn patients from the UK were not included as they were expected to have a HIC perspective on contracture risks, which was not the main focus of the study.

The interview guide and joint measurement protocol (collectively named the data collection tool - DCT) were piloted in advance of use in the final study. This chapter includes a report of the burn clinician interviews and the pilot study and describes how the findings of each informed the creation of the data collection tool used in the final study.

Figure 4-1: Schematic outline of the process of risk factor identification



4.2 INTERVIEWS WITH CLINICIANS

4.2.1 Introduction

The purpose of interviews with burn care professionals with LMIC experience was to augment the risk factors for burn contracture formation extracted from the literature and ensure the DCT would be appropriate to the study setting in Bangladesh. The views of these experienced clinicians were particularly important due to the paucity of primary LMIC research on burn contracture formation.

The semi-structured interviews aimed to identify what clinicians believed were the main risk factors for burn contracture formation in LMIC settings. Secondary aims were:

- i) to explore clinicians' views on contracture definition and measurement and seek additional LMIC-specific guidance on how to define and measure contracture for the purposes of this study
- ii) to explore whether burn care clinicians who worked in the LMIC context viewed contractures as preventable

4.2.2 Method

4.2.2.1 Sample and recruitment

Purposive sampling was considered the best method for selection of clinicians. This enabled selection of participants who were leaders in the field, came from a variety of countries and had significant experience in LMIC burn care including burn contracture management. Surgeons and therapists were preferentially targeted because i) the literature review demonstrated that surgeons and therapists were by far the most prolific writers on the topic of burn contractures and ii) in LMIC settings, these professions are the mainstay of the burns team with the greatest exposure to contracture management; the

large multi-professional teams seen in HIC healthcare are not a feature of LMIC burn care.

The inclusion criteria for participants were:

- Healthcare professional
- 3 years or more specialised experience in burn care / or substantially published in burn contracture management
- Currently work or have worked in burns care in a LMIC context
- Able to speak fluent English.

A shortlist of 25 burn care clinicians who met the above inclusion criteria was drawn from the extensive network available to The Global Centre for Burns Injury Policy and Research (GCBIPR) based in Swansea University, including leaders in burn care from LMICs who often visit GCBIPR for workshops and meetings. The schedule of workshops was considered in selection of potential participants to enable face-to-face data collection whenever possible, but interviews were also offered by phone or video-call. Shortlisted clinicians were contacted by email (Appendix 1) to assess their initial interest and availability during the 3-week study period in April 2019. The window for interviews was limited as the results had to be evaluated and incorporated into the DCT in time for the pilot study, which was planned for 2 weeks in May 2019.

Those who agreed to participate were sent email information on the study (Appendix 2) and a consent form (Appendix 3) to complete and return electronically.

4.2.2.2 Participants

Seventeen participants were recruited - 13 burn surgeons (3 general surgeons and 10 plastic surgeons) and 4 therapists (2 physiotherapists and 2 occupational therapists). Thirteen were from and currently worked in a LMIC.

The remaining four (2 therapists and 2 surgeons) worked in HICs, United States of America (USA) - 2, United Kingdom (UK) - 2 at the time of interview but had significant experience of working in at least one LMIC.

All participants had 3 or more years of experience specialising in burn care; average experience in burn care was 13 years (range 3–30 years). As caseload data were not available from their hospitals, participants were asked to estimate the numbers of patients they had treated, as an additional indicator of exposure to burn contractures.

Three participants were able to report the annual number of patients they saw. Of these, one treated 250 burn inpatients and >500 burn outpatients/year. This participant estimated that 200 of the 750 patients seen developed burn contractures. Another member of staff in the same institute (therapist) saw 250 inpatients/year and thought 60% of these patients had contractures. The third participant treated 1000 burn patients/year, of whom an estimated 50% developed contractures. Four participants responded by estimating the numbers of patients seen per week (from 1-2 to 30-40) or per month (15-20). Five participants captured their exposure by providing an approximation of how many burn contracture patients they had seen over their career to date, estimated as “several 1000s”, “100s”, “100s”, “350”, and “15,000”. Although anecdotal, these data support the hypothesis that contracture is a common problem after burns in LMIC, and that the clinicians interviewed had considerable experience with burn contractures.

Work Location

The countries represented by participants were Ghana (n= 2), Ethiopia (n= 3), Malawi (n = 1), Nigeria = (n=1), South Africa (n= 1), Nepal (n =2), India (n= 3). The 4 participants currently based in HICs worked in the UK (2) and USA (2) but had LMIC burn care experience in Nepal, Togo, Sierra Leone, Bangladesh,

Cote D'Ivoire, Ethiopia, Ghana, Haiti, India, Indonesia, Sri Lanka, Zambia collectively. Apart from one surgeon and one therapist who worked in the same institute in India, each participant represented a different burn care institution.

Most participants worked in urban settings ($n = 10$). Five worked in both urban and rural settings and 2 worked only in a rural setting.

Most participants worked in tertiary care ($n = 13$), 3 participants worked in all levels of healthcare, and 1 participant worked in the Ministry of Health. Two participants worked in private hospitals and 3 in Non-Governmental Organisations, but the majority ($n=12$) worked within the Government healthcare systems of their respective locations.

One participant provided only paediatric burn care; all other participants treated children and adults. All participants treated both acute and reconstructive burn patients.

4.2.2.3 Interview process

Fourteen of the 17 participants were interviewed face-to-face by the researcher in GCBPR, Swansea, during their visit to the centre. The remainder ($n=3$) were interviewed by WhatsApp call from a private space.

The semi-structured guide for the expert interviews was developed by the researcher to collect participant information, elicit participants' views on the risk factors for burn contracture, explore their preferred methods of contracture measurement and explore related topics such as their beliefs regarding the prevention of burn contracture formation. The interview guide used is shown in Appendix 4.

All questions were open-ended. No direction was given by the interviewer with respect to possible or expected answers, other than to encourage participants to think as broadly as possible in regard to potential risk factors.

Questions to capture participant views on risk factors for burn contracture formation were asked from several angles, for example, "What if anything does the presence of a contracture tell you about a patient or their care?", and "What do you think are the risk factors for burn contracture formation?". Participants were also shown a photo of a severe burn contracture and asked to outline the risk factors that they anticipated had led to the development of the contracture.

Participants tended to list or mention risk factors rather than provide details or explanations, for example, 'lack of surgery', 'no splinting', 'lack of compliance to treatment or advice'. Participants reported potential risk factors either in a negative sense (risk), e.g., "no splinting" or in a positive sense (protective) e.g., "access to early splinting". Sentences or statements of interest reported by participants were also captured, some of which are reported in Figure 4-2. Interviews were completed in 30-60 minutes and were audio-recorded with consent from participants.

4.2.2.4 Data management and analysis

All data were collected anonymously and stored securely. The researcher listened to the recordings and reviewed the data collected to enable content analysis. Any stated risk factor was only transferred to the spreadsheet once per participant, regardless of how many times it was mentioned. All risk factors given by participants were assigned to categories; initial categorisation of the potential risks identified was based on what best fit the data rather than utilising categories which emerged from the literature review.

The frequency with which a risk factor was cited was recorded i.e., if 3 participants reported 'lack of skin graft' as a risk for contracture, this factor was given 3 points. Participants were also asked to name risk factors which, in their opinion, were the top 5 most important or influential for burn contracture formation. A list was created of all the factors mentioned in response to this question, then each factor was scored according to the number of participants who mentioned it as their first, second, third, fourth, or fifth choice. The total scores for each risk factor allowed them to be ranked in order of popular opinion.

4.2.2.5 Ethical considerations

Ethical approval for the expert interviews was included in Phase 1 of the Ethics Application to Swansea University, which was granted 11th April 2019 (Appendix 5).

4.2.3 Results

4.2.3.1 Risk factors

Eighty-seven risk factors for contracture formation in LMIC environments were suggested by the 17 clinicians. Participants did not report any independent protective factors. The categories of risk factors which emerged from the clinician interviews were:

- a) **Person/non-burn:** factors specific to the person but not burn-related, such as age, treatment adherence, co-morbidities
- b) **Person/burn:** factors directly related to the burn injury, such as TBSA, depth and location of burn
- c) **Family and community:** factors related to the family or community of the patient, such as lack of awareness of burn injuries, illiteracy

- d) **Treatment factors:** factors related to treatment of the burn, such as lack of skin grafting, lack of splinting
- e) **Complications:** factors related to complications of the burn or treatment, such as infection or graft failure
- f) **Healthcare capacity:** factors related to the broad healthcare system, such as lack of primary prevention, lack of training of burn care team
- g) **Societal and environmental:** wider problems such as low socio-economic status, lack of political support for burn care.

The nature, categorisation and frequency of all reported risk factors is shown in Appendix 6. Overall, 43 factors were suggested by more than one respondent; 10 was the maximum frequency of report for any individual risk factor. Table 4-1 shows the 10 risk factors mentioned most frequently by the 17 participants.

Table 4-1: Top ten risk factors most frequently cited by clinicians

Risk Factor	Frequency of Report
Lack of splinting	10
Lack of adherence to care by the patient / family	9
Biology of the patient / tendency to scar	8
Location of burn	8
Lack of trained staff	8
Depth of burn	7
Wound infection	7
Delayed treatment	6
Lack of physiotherapy	6
Lack of positioning	6

Of the top 10 most frequently cited risk factors, 5 related to perceived deficiencies in provision of appropriate treatments, including systemic failures (delayed treatment and lack of trained staff).

The most frequently reported risk factors were slightly different from those which emerged as the highest scoring factors when the clinicians were asked

to rank their personal ‘top 5’ most important contributing factors for contracture formation (**Error! Reference source not found.**). A total of 31 different risk factors were selected by the 17 clinicians as being within their ‘top 5’ most important for contracture formation in their LMIC settings. **Error! Reference source not found.** shows the 20 most cited risks identified from each clinician’s ‘top 5 most important’, along with the frequency of inclusion and the overall ranking.

Table 4-2: *The 20 most important contracture risk factors identified by clinicians*

Factors cited by Clinicians as the “Top 5” contributors to contractures in LMICs	No of times included in “Top 5” Choices	Ranking Score	Rank	Category of Risk Factor
Lack of splinting	9	32	1	Treatment
Lack of physiotherapy	6	24	2	Treatment
Lack of early excision and grafting	5	18	3	Treatment
Infection	5	17	4	Complication
Delayed wound closure	4	17	4	Complication
Low socioeconomic status	5	12	6	Socioeconomic
Poor patient education	4	11	7	Socioeconomic
Location of the burn	4	11	7	Burn
Poor compliance with treatment	3	9	9	Patient/ burn
Poor positioning	2	9	9	Treatment
Lack of timely access to appropriate Rx	3	8	11	Health system
Inadequate pain control	3	8	11	Treatment
Lack of family support	2	8	11	Socioeconomic
Inadequate resuscitation	2	7	14	Treatment
Depth and extent of burn	2	6	15	Burn
Lack of pressure garments	2	5	16	Treatment
Financial pressures	1	5	16	Socioeconomic
Lack of dedicated burn unit	1	5	16	Health system
Lack of movement	1	5	16	Treatment
Inadequate expertise/training of the team	2	4	20	Health system

Eight of the top-ranked factors were related to treatment deficiencies or failures. However, 4/20 factors related to socioeconomic issues affecting patients and/or their families and 3/20 to health system deficiencies or failures. Of the 31 factors included in the clinicians' 'top 5', over one third (11/31) were socioeconomic (n=6) or health system problems (n=5). The perceived contribution of these types of risk factors to burn contracture formation in LMICs therefore seems much greater than observed from HIC literature.

A striking quote from one participant reflects the range of risk factors reported: "Contractures are due to lack of resources, lack of education, lack of suitable environment – lack of everything."

4.2.3.2 Definition and measurement of burn contracture

The clinicians were also asked for their definition of a burn contracture, either in their own words or by quoting from literature. None gave a technical or textbook definition; all used their own words to define a contracture. All participants appeared confident to provide a definition that they were satisfied with; none of the definitions provided were inconsistent with the literature, but there was considerable variation in approach. The range of definitions given by participants is illustrated in Figure 4-2 below; some described only anatomical features and others included functional effects.

Sixteen participants were confident that they would be able to identify a burn contracture clinically. Ten added a further affirmative to their positive answer, such as "...absolutely" (n=3), "...no doubt" (n=4), "...definitely" (n=2), "...it is very easy" (n=1). The only participant who expressed doubt in identification of a contracture answered, "...sometimes it is difficult to be sure".

There was considerable variation in the methods described by the clinicians to identify a contracture (Figure 4-2); it also appeared that participants did not

necessarily use these methods in their own practice. For example, a participant reported that they would identify a burn contracture by reduced function but did not report the use of any standard functional assessment tool or outcome to measure function in their practice. Therefore, although participants were confident to report a conceptual definition, they were not able to provide any operationalised definition or measurement system that was used routinely in their clinical practice.

Figure 4-2: Definitions of contracture offered by clinicians

Anatomical definitions (each bullet point reflects an individual respondent)

- *Where there is not full range of moment at any joint*
- *Excessive fibrosis tissue secondary to burn occurring across a joint*
- *Muscular contracture due to skin and muscle and tendons that contract causing limited movement*
- *Any restriction to normal anatomical movement, abnormal adhesion of tissues*
- *Deficit of tissues, including skin, fascia, and subcutaneous. There is an imbalance between skeletal structure and the soft tissue and range of movement is limited*
- *Any limitation in movement or any deformity in feature*
- *Affected mobility of a joint, or in a facial contracture the pulling of a feature*

Functional definitions (each bullet point reflects an individual respondent)

- *Scar that limits movement and has a functional impact*
- *Loss of range of movement that affects function after wound healing*
- *Limited range of movement to some degree that has impact on function*
- *Shortening of the skin and or the tendons leading to a limitation in the normal function of that joint or part of the body*
- *Shortening of soft tissue usually found across joints which leads to loss of function, deformity, tightness in the joint and depending on the stage of the contracture it can lead to limited or no movement of the joint*
- *Injured skin loses its elasticity and there is tightness of the skin, this leads to reduced range of movement and functional impairment. So, any tightness that means a loss of range is a contracture*

Participants were asked if they had experienced any difficulty in burn contracture measurement. Twelve participants reported no difficulties; one

participant (surgeon) delegated all contracture measurement to her therapist and was unable to answer. Three therapists and one surgeon reported the following difficulties in contracture measurement:

- poor reliability of goniometer measurements
- poor patient compliance and pre-existing reasons for limited range of movement
- fear of movement by the patient
- compensatory movements by the patient which interfered with joint measurement
- the impact of the position of the adjacent joints on the joint being measured if the scar crosses more than one joint.

One participant reported “each contracture is so different” and that she “could describe a contracture consistently, but the next person would report a different description”. She suggested a measurement guideline was required but that this did not exist currently and would be complex to produce. This sentiment is captured by this quote: “It may be difficult to define it [a burn contracture] but you know it when you see it”.

Although participants referred to various ways a contracture could be measured (Figure 4-3), no participant could describe a measurement protocol or give a standardised operational definition of a contracture. When general topics of measurement were discussed (such as loss of range, loss of function, patient opinion), no standardised methods to capture these constructs were mentioned.

Figure 4-3: How clinicians assessed contractures in practice

Q: Can you explain how you would identify a contracture clinically?
<ul style="list-style-type: none"> • There are those contractures that incapacitate a patient and those that do not • How much of the anatomical area has been involved • How much limitation of range
<ul style="list-style-type: none"> • Functional, aesthetic, or social limitation • Limited movement, impaired function • Limits function and may be yielding or unyielding, permanent or not permanent • Any tightness of the skin or loss of elasticity is a contracture even if there is no loss of range or function
<ul style="list-style-type: none"> • Usually there is a lack of extension, there is a loss of function and range of movement, measured with a goniometer • There are contracture classifications (not able to name any specifically) • Loss of range of movement • Type of scar e.g., thin scar band, thick scar band
<ul style="list-style-type: none"> • Measure the range of movement (angle), measure quality of life (no specific scales given), measure impairment of function (no measures given) • Height of contracture (scar), colour of the scar, the feel of the contracture, yielding of the scar, whether the scar has rods / bands
<ul style="list-style-type: none"> • Measure impairment of function (no measures given) • Range of movement – mentions the need to check the position of other joints • Passive and active movement • Whether the contracture is fixed or not
<ul style="list-style-type: none"> • Scar assessment – pliability, contractility • Look at ligament structures • Assess movement through active or passive joint • When assessing range of movement, it is necessary to check the position of other joints • Observe function ability and compensatory movements • Observe confounding factors (to movement) such as pain • Assess if the contracture is yielding or not
<ul style="list-style-type: none"> • If the patient struggles to do a functional task, then I classify that contracture as severe • Range of movement • Vancouver scar scale
<ul style="list-style-type: none"> • Condition of the skin • Range of movement and functional ability • Therapists measure range with a goniometer, but I [surgeon] am unable to use one reliably • Patients' perception as to if the contracture is problematic or not
<ul style="list-style-type: none"> • Assess tissue deficit • Loss of movement and function • Depth, width of scar • Whether single or multiple joints are involved with the contracture • I don't use any grading or classification system for contracture measurement, I am more interested in what the perception of the patient is

When asked which measurements the participants used in their practices and how this was documented, only 4 clinicians used any objective measure for contracture. These four (3 therapists and 1 surgeon) used goniometer measurement, but no specifics or protocols were given. Two of those who used goniometer measurement, did so “when possible” and suggested that it was not routine practice. These 2 participants preferred visual estimation (“eyeball”) of the angle rather goniometer use. One therapist was conducting research into contracture measurement at his institution; the measures he used were a) goniometry b) a scar scale (which he was unable to name) and c) activities of daily living (ADL) score, using a functional measure, which he was unable to name.

None of the participants worked in an institution where any data were collected on the incidence or severity of burn contractures at department or hospital level. Only 5 participants (4 therapists and 1 surgeon) reported documenting contracture measurements in their patient notes.

4.2.3.3 Timing of burn contracture formation

The clinicians were also asked their opinion on when a contracture was first noticeable and when a contracture was unlikely to change further. This was to further inform the inclusion criteria for the study, so that participants were not included before a contracture was likely to have presented. Little was available in the literature to inform this decision. In addition, it was interesting to see whether clinicians’ views on when a contracture became fixed would correspond with the time post-burn that the pathophysiological theory of scar maturation would suggest (i.e., around 2 years) which was also an inclusion criterion for the reconstructive group.

Participants reported a range of 1 – 8 weeks as the time that a contracture may first become apparent; the average reported time was 2.5 weeks. Regarding

the time at which a contracture became ‘fixed’, the average response was 8.5 months with a range of 6-18 months. Two participants added that the time at which a contracture became fixed would depend on the location of the burn, stating that eyelids and hands were more likely to contract earlier. Age of the patient was cited by three participants as a factor that affected the time at which a contracture became fixed (earlier if the patient was younger). One participant reported that severity of contracture would influence the point at which a contracture would become fixed - “It [a contracture becoming fixed] relates more to severity than time, so if it is a moderate contracture, it is unlikely it will go away”.

Ten participants reported that the initial stage of care (first 4 weeks) post-burn is the timeframe during which the outcome of a contracture can be most influenced. Three participants indicated that the first 3 months was the most influential period; 4 participants did not respond.

4.2.3.4 Preventability of burn contractures

Participants were asked if they thought contractures were preventable. Eight participants responded “yes”; of these, five added a “definitely” or “absolutely”. All others indicated that most contractures were preventable theoretically, but provided less emphatic and more nuanced responses, as evidenced by the quotes below:

- “In the ideal situation most contractures can be prevented”
- “Due to the big burden of burns it is difficult. If we had a multipronged approach to access and effective treatment [for the burns patients] then it would be possible to prevent it [burn contracture]. The task is not simple.”
- “In the medical world we all accept that contractures are preventable, but there are multifactorial causes, some are more difficult to address

than others If the patient presents to healthcare, they are preventable, but not if they don't present to healthcare I wouldn't say that we can prevent all contractures, but they are ALL preventable."

- "Yes, overall if you had everything that you could throw at it [burn care/contractures], with the multidisciplinary team working, then yes. But no in certain contexts – it depends on the resources available."
- "There are too many variables at play in summary it is not a yes or no question, it depends."
- "When a contracture has developed – someone has missed an opportunity."

4.2.3.5 Formation of clinical opinion

To indicate how much weight clinicians gave to published literature compared to clinical experience, participants were asked what sources of information informed their knowledge on risk factors for burn contracture formation. Fifteen participants said, "Mainly from clinical experience"; one participant reported "mainly from literature". Of the fifteen participants relying mainly on their clinical experience, three provided further quantification – "from experience 80% and 20% literature", "100% from clinical experience", "70% from clinical experience and 30% literature". None of the participants were able to mention an article or specific publication that had helped formulate their opinions.

4.2.3.6 Summary of clinician interview results

The clinicians interviewed appeared very confident to talk about contractures and had strong opinions. They identified a very large number of risk factors covering a broad spectrum of domains including the burn itself, the patient, and a range of treatment, health system and socioeconomic factors.

Although participants had no doubts that they could recognise a contracture, none provided a standardised system of measurement or an operational definition of contracture.

Goniometry was rarely used in routine practice; visual estimation was usual. None of the institutions represented by participants collected any data on contracture prevalence, outcome, or treatment.

Most clinicians believed contractures are preventable in that all risks could theoretically be controlled so that a contracture did not develop. However, despite this belief there was also acceptance that contractures often did develop, due to the multiple challenges faced in low resource settings, with many risk factors being outside the clinicians' control. The clinicians learned more about contractures and what influences them from their own experience rather than from the literature.

4.2.4 Key Findings

4.2.4.1 Risk factors

The range of risk factors reported by the clinicians was very broad and included factors which had been extracted from the literature review, but also added further factors not previously documented. Most additional risk factors generated by clinicians were non-treatment factors, relating more to socio-economic factors and healthcare system factors, again highlighting the potential impact of the social determinants of health (Commission on Social Determinants of Health, 2008). The fact that most of these LMIC clinicians relied on personal experience rather than literature to identify risk factors for contracture is in keeping with the findings from the literature review where putative risk factors were predominant. It also emphasises the need for wider research and publication on risk factors for contracture in LMIC settings.

Not all risk factors extracted from clinicians were suitable for evaluation within the scope of the planned study. Risk factors relating to capacity of the healthcare system, socio-economic and environmental factors were the categories most difficult to capture within the limitations of the study design. Most of the potential risk factors identified in the person/non-burn, person/burn, family & community, treatment, and complications domains could be included in the pilot data collection tool.

4.2.4.2 Preventability of contracture

Most clinicians were adamant that contractures were theoretically preventable although, as suggested by the quotes above, the responses became less emphatic and more dependent on a broad range of factors. Although the perceived preventability of contractures is not directly relevant to the DCT, it supports the belief that some risk factors could be modifiable and lends justification to the basic purpose of this thesis.

4.2.4.3 Definition and measurement of contracture

The clinician interviews did not alter the proposed definition and measurement protocol developed from review of literature.

4.2.4.4 Limitations

Although 17 is a small sample, it was felt that sufficient data had been achieved with this sample size. As the interviews progressed, no new risk factors were offered. Although the selection of doctors and therapists as participants reflects the authorship of articles included in the literature review, other burn team members, such as nurses and psychologists, might have given useful or different input. Expanding the interviews to more members of the multidisciplinary team could have been beneficial if time had allowed.

The emphasis of participants on non-treatment risk factors could be a bias inherent to data collection through interviews, especially face-to-face interviews, with clinical professionals. Participants may have preferred to focus on risk factors outside their control (e.g., patient characteristics, socio-economic healthcare access factors), rather than on those for which they are more directly responsible, such as treatment factors. Alternatively, the emphasis on non-treatment factors may be more relevant in the LMIC settings from which participants were reporting; this is very different from the usual focus on treatment-related factors in HIC. Participants also knew the interviewer was a physiotherapist, which may have consciously or subconsciously influenced them to report risk factors supporting the role of therapy within burn care; lack of positioning, lack of splinting and lack of physiotherapy were amongst the most cited risk factors.

4.3 DESIGNING THE DATA COLLECTION TOOL

4.3.1 Developing the Interview Guide

4.3.1.1 Inclusion of risk factors

The risk factors extracted from the literature review and the clinician interviews were collated for inclusion in the pilot study interview guide. An attempt was made to include all reported risk factors, even if reported only once. However, some exclusions were necessary; a risk factor was excluded if it could not be explored within the planned study, either because it was outside the scope of the study (e.g., assessment of the training and expertise of the burn care team) or was unlikely to be identifiable through patient report or medical documentation (the anticipated sources of data for the proposed study).

The following criteria were used to select and operationalise the risk factors to be included in the DCT:

- a) Each risk factor should be transferable into a question that could either be asked of the participant and/or retrieved from participant's medical notes. For example, on skin grafting, the question asked to the participant was "Have you had a skin graft?", but medical notes would also be examined for evidence of any skin graft, (including type and date) and/or graft failure. Researcher observation would be used to triangulate with the reported sources.
- b) Any question used to explore a risk factor should be understandable to participants unfamiliar with medical terms, should be as simple as possible, and should not convey any sense of blame or cause concern to the participant.
- c) Although the questions would be open wherever possible, they should be constructed to generate a quantitative or categorisable answer wherever possible to enable quantitative data analysis and for ease of data collection.

There were limits to the extent to which some risk factors could be explored in the pilot study. For example, psychological problems are cited as a risk factor, but in the study, it would only be possible to examine this from patient reports or medical documentation. The exploratory question was included in the interview guide as "How have you been feeling since the burn injury, how is your mood?". A question on whether the participant had seen a counsellor or not was also included. It was not possible to make any further assessment of this potential risk factor. Table 4-3 shows the risk factors to be included in the pilot study.

Table 4-3: Sources of risk factors included in the pilot study

Risk Factors	Literature Review	Clinician Interviews	Pilot Study
Demographic Factors			
Gender	✓	☒	✓
Ethnicity	✓	☒	✓
Age	✓	✓	✓
Rural or urban residence	✓	✓	✓
Geography limiting access to care	☒	✓	✓
Socio-economic Factors			
Low socio-economic level	☒	✓	✓
Poverty	✓	✓	✓
Ignorance	✓	☒	☒
Lack of intelligence	☒	✓	☒
Illiteracy	☒	✓	✓
Education level	✓	✓	✓
Level of maternal education	✓	☒	✓
Lack of ability to pay for care	☒	✓	✓
Lack of family support	✓	✓	✓
Social mockery	✓		☒
Lack of basic infrastructure such as electricity, requiring open fires	☒	✓	☒
Lack of autonomy for women	☒	✓	☒
Person/Non-burn			
Co-morbidities	✓	✓	✓
Biology of patient/tendency to scar	☒	✓	☒
Learning impairment	☒	✓	✓
Lack of intelligence	✓	✓	
Psychological problems	✓	✓	✓
Psychiatric history	☒	✓	✓
Low mood	☒	✓	✓
Pain threshold	✓	✓	✓
Fear/anxiety	✓	✓	☒
Lack of awareness re: burn injury and treatment	✓	✓	✓
Adherence to treatment	✓	✓	✓
Muscle weakness	✓	✓	☒
Lack of personal hygiene	☒	✓	☒
Belief the patient will die	☒	✓	☒
Cultural beliefs	☒	✓	☒

(✓ included ☒ not included)

Table 4-3: (continued)

Risk Factors	Literature Review	Clinician Interviews	Pilot Study
Burn Injury Factors			
First aid	✓	✓	✓
Cause of burn	✓	☒	✓
TBSA of injury	✓	✓	✓
TBSA of each depth of burn	✓	☒	✓
CFU involvement	✓	☒	☒
Age at time of injury	✓	☒	✓
Depth of Burn	✓	✓	✓
Location of Burn	✓	✓	✓
Inhalation injury	✓	✓	✓
Oedema	✓	☒	✓
Delayed wound healing / wound closure	✓	✓	✓
Low albumin and protein levels	☒	✓	☒
Tension over wounds	✓	✓	☒
Infection	✓	✓	✓
Pain	✓	☒	✓
Neuropathy	✓	✓	✓
Hypertrophic ossification	✓	☒	✓
Amputation	✓	☒	✓
Thick scars	✓	☒	✓
Healthcare Access			
Incomplete/ineffective treatment	✓	✓	✓
Reliance on traditional healers	☒	✓	✓
Lack of healthcare facility utilisation	✓	✓	✓
Lack of healthcare facilities	✓	✓	☒
Level of health facility accessed	✓	☒	✓
Place of initial treatment	✓	☒	✓
Treatment in rural healthcare	✓	☒	✓
Poor referral system	✓	✓	✓
Time from injury to hospital care	✓	✓	✓
No/Delayed specialist care	✓	☒	✓
Length of stay	✓	☒	✓
Complicated hospital stay	✓	☒	☒
Incomplete / ineffective treatment	✓	☒	✓
Lack of follow up	✓	✓	✓
Lack of trained staff	☒	✓	☒
Lack of resources	☒	✓	☒

(✓ included ☒ not included)

Table 4-3: (continued)

Risk Factors	Literature Review	Clinician Interviews	Pilot Study
Healthcare Access (contd.)			
Lack of MDT burn team	☒	✓	☒
Poor attitude of healthcare workers	☒	✓	☒
Lack of focus on good outcomes / focus on saving life rather than quality of life	☒	✓	☒
Cost of burn care	☒	✓	✓
Early discharge due to lack of finance	☒	✓	✓
Lack of quality care	☒	✓	☒
Lack of Government support for finance and healthcare	☒	✓	☒
High volumes of patients	☒	✓	☒
Treatment Factors (Surgical/Medical)			
Escharotomy	✓	☒	✓
ITU stay	✓	✓	✓
Skin grafting	✓	☒	✓
Time to skin graft	✓	✓	✓
Graft type	✓	☒	✓
Graft failure	☒	✓	✓
High TBSA grafted	✓	☒	✓
Refusal to have skin graft	✓	✓	✓
Number of surgical procedures	✓	☒	✓
VTE prophylactic treatment	✓	☒	☒
Anabolic agent administered	✓	☒	☒
Lack of nutrition	☒	✓	✓
Lack of pain management	☒	✓	✓
Delayed reconstruction	☒	✓	✓
Poor dressings	☒	✓	✓

(✓ included ☒ not included)

Table 4-3: (continued)

Risk Factors	Literature Review	Clinician Interviews	Pilot Study
Treatment Factors (Rehabilitation)			
Lack of physiotherapy	✓	✓	✓
Delayed physiotherapy	✓	☒	✓
High rehab time input	✓	☒	✓
Low ratio of rehab to hospital days	✓	☒	✓
Lack of positioning	✓	✓	✓
Lack of mobilisation	✓	✓	✓
Prolonged immobilisation	✓	☒	✓
Lack of exercise	✓	✓	✓
Lack of splinting	✓	✓	✓
Lack of scar massage	✓	✓	✓
Lack of pressure therapy	✓	✓	✓
Lack of silicone gel	✓	✓	✓
Length of time of splint / positioning	✓	☒	✓
Functional tasks	✓	☒	✓

(✓ included ☒ not included)

4.3.1.2 Whole person vs joint-specific questions

As described in 3.9.6, potential contracture risk factors may be explored at either 'person' level or 'joint' level. Risks which should be considered at 'person' level are those factors that relate to and/or affect the whole participant, such as demographic and socioeconomic factors, distance and time to initial treatment, co-morbidities and length of hospital stay. These would not vary for any joints at risk in an individual participant.

Potential risk factors such as having/not having a skin graft or splinting can be captured at person level but would not represent the situation accurately;

some joints at risk may have received these interventions while others did not. Therefore, risk factors most relevant at joint level were also collected for every joint at risk. These risk factors were mainly treatment-focused factors such as presence or absence of infection, skin grafting, splinting, positioning and pressure. If a risk factor was relevant at joint level as well as person level, the relevant question would also be asked for every joint at risk, during the flow of the interview and responses entered into separate 'person' and 'joint' databases for subsequent analysis.

It was decided to create two interview guides, one for acute participants, who could only answer questions relating to their injury and treatment up to the point of interview, and a second for the reconstructive group who could report on a broader range of potential risk factors such as those pertaining to the full hospital stay, discharge, and follow-up care. As the reconstructive group would have a longer history to relate and were in a more stable condition, a decision was made to trial more open-ended questions in reconstructive interviews than in acute interviews. For example, rather than asking whether the participant had a specific treatment (e.g., skin grafting or physiotherapy), the questions was phrased as "Can you tell me what you remember of the treatment you had?", and rather than being asked specific questions about discharge and follow-up, reconstructive participants would be asked "Can you tell me what you remember about what happened after your hospital treatment?" Following these open-ended questions, the reconstructive guide also reverted to specific questions as in the acute guide, in case all relevant risk factors were not covered by the participant's initial response to the open questions.

4.3.1.3 Operationalisation of risk factors

Some risk factors could be clearly stated in a question, (e.g., “Do you know what depth or how deep your burn was?”) and the response triangulated with medical documentation and where possible, direct researcher observation. Other factors such as co-morbidities could be captured in a single question (“Do you know if you have any other health problems that affect your body or your mind, other than the burn injury?”) and be further informed by medical documentation and researcher observation.

However, some potential risk factors, such as ‘lack of physiotherapy’ had to be addressed through several questions in order to establish whether any physiotherapy which might have been provided was likely to be adequate and effective. Lack of physiotherapy in the pilot interview guide was therefore covered with several questions:

- “Have you seen a physiotherapist?”
- “How long after your injury / admission did you see a physiotherapist?”
- “About how long was each visit from the physiotherapist?”.

Questions were also asked about specific physiotherapy interventions such as splinting and exercise, which were examined as separate risk factors, but also informed the broader issue of lack of adequate/appropriate physiotherapy.

Consideration was given to how to determine the likely efficacy of interventions reported by participants, which might not have been effective. For example, the simple provision of a splint or garment does not mean the participant was able to use or wear the appliance effectively; consequently, although the intervention might have been offered, the potential risk factor (lack of effective splint/pressure) was still present. Therefore, a list of supplementary questions was developed to indicate whether an intervention was likely to have been effective, including when the intervention started, how

long it was applied, and participant description/demonstration of the intervention.

Several risk factors required further clarification, such as wound infection. Although infection could be formulated into a single question ("Did any of your wounds become infected? "), more definitive evidence of infection was required. Although participants might report signs and symptoms consistent with infection, most of these could be associated with the acute burn itself and would not themselves confirm the presence of infection. The only definitive evidence of infection would be a microbiological report of a wound swab, but it was not known if these would be available at the study site. Investigation of the presence of 'infection' would therefore require further on-site assessment during the pilot study. Similarly, the potential risk factor 'lack of nutrition' could be defined in several ways, but as the level of medical documentation and investigation at the study site was not known, the operationalisation of this risk factor could only be done during the pilot study.

Some potential risk factors could not be phrased as a direct participant question but could be examined indirectly. For example, the cited risk factor of 'poor referral system' was not an appropriate question for participants, but information could be gathered from combining their answers to other questions. For example, participants were asked where they went for their first treatment; each treatment stop and the reasons for moving from one health facility to another (or reasons for not moving if a transfer was recommended but refused) were documented. The mode of transport, cost of transportation and distance between stops was also documented. From the answers given, a picture could be built of the efficiency and effectiveness of the referral system.

Several risk factors would rely more on researcher observation than patient report or medical documentation. Examples include presence of oedema,

neuropathy or hypertrophic ossification; participants could not be expected to understand these terms and unless documented in medical notes, these potential risk factors would only be identified from direct researcher observation.

Consideration was given to the definition and operationalisation of risk factors prior to the pilot study. However, final decisions were developed through an iterative process as more data were collected and after data evaluation. The same definitions and operationalisations were ultimately applied to all data collected and were standardised across all participants.

Decisions were also required on how to express timeframes. This was also an iterative process as more data were collected. Examples were how to quantify time post-burn (months or years), time to first physiotherapy (days, weeks, or months), time to first graft (days or weeks), and length of hospital stay (days or weeks).

4.3.1.4 Participant opinion and awareness

In addition to the risk factors gleaned from the literature review and clinician interviews, it was considered useful and interesting to gain participants' views on risk factors for burn contracture formation during the pilot study.

To this end, a Focus Group Discussion (FGD) was planned to explore participants' opinions on their burn contracture formation. The FGD would also give an opportunity to test participants' understanding of terms to be used in the semi-structured interviews and assess their ability and willingness to discuss and remember past events associated with the burn. It would also show if a FGD could be an effective data collection tool in the final study.

Ideally, the FGD would have been conducted prior to piloting the interview guide to enable earlier participant input into the study, however it was not

possible to justify an additional field trip for this purpose, therefore the FGD was scheduled for the first research day of the pilot study. It was anticipated that any changes to the interview guide informed by the FGD could be made on site. Participants were also asked what risk factors they thought should be included in the study to prevent burn contracture in the future.

4.3.1.5 Other data included in the interview guide

The DCT also included data about the research process such as the name of the translator, duration of interview, and participant study number. A few rapport-building questions were also included such as 'Are you married?' and 'Do you have any children?'. Additionally, some supplementary 'why?' questions were included to shed light on participants' reasons for decisions such as not seeking treatment, refusing a skin graft, self-discharge or not attending follow-up.

4.4 Data Collection

A system called Open Data Kit (ODK) <https://opendatakit.org> for onsite data collection and entry was used. Due to the relatively uncontrolled research environment and the large amount of data to be collected from multiple sources, it was important to channel collected data into one single location at the point of interview. ODK provides software to help researchers collect and manage mobile data collection and is targeted for use in resource-limited settings (Hartung et al., 2010). ODK is an App based programme, available on Android and accessed via a mobile phone or tablet. Data can be collected offline and synced when a reliable and secure connection is available. ODK was introduced in 2008 and is now utilised by many humanitarian organisations such as the World Health Organisation and the Red Cross.

The ODK platform favours quantitative data collection. Data input can be typed or pen-written text, photos, voice recordings or multiple-choice

selection of pre-programmed answers. For the present study, a customised system based on the interview guides and planned joint measurement protocol was built by this researcher. Where possible, pre-programmed responses were anticipated and built in. Separate ODK forms were constructed for acute and reconstructive participants, which are illustrated in Appendices 7 and 8 respectively, showing both the questions asked and the pre-categorisation of answers. These forms included description of the areas involved in the burn injury and the joints at risk. A third ODK form (Appendix 9) was designed to capture the measurements of each joint at risk. These forms were housed in the ODK App held on the researcher's Samsung tablet. On completion, the data can be exported from ODK, via a CVS file into Excel and SPSS for data analysis.

4.4 PILOTING THE DATA COLLECTION TOOL

4.4.1 Introduction

It was considered vital to pilot the customised DCT prior to the final study.

The aims of the pilot study were to

- a) Conduct a FGD to gain understanding of terms and seek participants' opinions on risk factors for burn contracture
- b) Pilot the interview guide
- c) Pilot the joint measurement protocol
- d) Test the functionality of ODK
- e) Pilot recruitment and data collection procedures
- f) Collect data using the DCT to assess the proposed data analysis system
- g) Familiarise the researcher with the local research environment
- h) Consider logistical issues for the research, including securing appropriate interpreter input

- i) Build relationships with hospital management and gain their approval/input into the research design

This section describes the pilot study and how the findings of the pilot informed the final study. The pilot study was conducted at DMCH, for two consecutive weeks in May 2019.

4.4.2 Method

4.4.2.1 Study population and recruitment

The pilot study population comprised any patient who met the inclusion criteria and attended DMCH as either an inpatient or an outpatient. The study population included 2 groups, termed 'acute' and 'reconstructive'; the aim was to interview 10 participants in each group. The acute group were in the first phase of burn care, still had burn wounds and were inpatients. The reconstructive group were either inpatients who had been admitted for contracture release, or outpatients with a contracture requiring reconstruction. The reconstructive group had healed burn wounds and had been previously discharged from acute care. Inclusion criteria, sampling and interview guides differed for both groups.

It was determined that the FGD should include only reconstructive participants. For logistical reasons, only inpatients were appropriate for FGD inclusion; the time for outpatients to participate in the FGD was too limited. The reconstructive group was selected for a FGD because the patients were not in an acute situation, could be seen together (unlike acute patients where infection control had to be considered), had experience of contractures (as they all had at least one) and could report on their experience on all potential risk factors included in the study, due to the longer time since the burn.

4.4.2.2 Acute group inclusion criteria

1. 18 years or older
2. Patient is admitted to DMCH with a burn injury
3. Patient has a survivable burn and is medically stable
4. Date of the burn is >4 weeks prior to date of recruitment
5. At least one major joint (neck, shoulder, elbow, wrist, hip, knee, ankle) is at risk (i.e., the burn was of sufficient depth and location to be a risk for contracture formation)
6. Patient consents to be involved in the study and has no cognitive, intellectual or physical impairment affecting oral communication or memory
7. Medical notes are available
8. Any loss of range at the study joint is due to scarring/burn rather than to another pathology or confounding factor
9. The movement required to measure the range of movement of the study joint is not contraindicated for any reason (such as recent skin graft requiring joint immobilisation)

4.4.2.3 Reconstructive inclusion criteria

1. Is 18 years or older
2. Is admitted to DMCH for contracture release at a major joint (neck, shoulder, elbow, wrist, hip, knee, or ankle) OR is attending outpatients at DMCH with a burn contracture requiring surgical release
3. Consents to be involved in the study and has no cognitive, intellectual, or physical impairment affecting oral communication or memory, and is able (or has a relative who is able) to give a history of the injury and subsequent treatment

4. If participant is an outpatient, s/he must be able to give the time required for recruitment, consent, and participation process without detriment to their outpatient care or return journey home

4.4.2.4 Inpatient sampling and recruitment

Acute Burn Participants

The hospital is divided into four zones managed by different consultants, each comprised of a number of single-sex adult and mixed-sex paediatric wards. The average daily number of inpatients in the Burns Unit of DCMH during the pilot study was 547. Convenience sampling was used for daily zone and ward selection. A new zone was not selected for sampling until all consenting participants on the shortlist had been interviewed.

No electronical medical records with patient information were available and the paper medical notes on each ward were also insufficient to determine which patients met the inclusion criteria. Due to this lack of medical documentation, a visit to potential participants was necessary to confirm eligibility.

Reconstructive Participants

Due to the limited number of reconstructive patients admitted during the pilot period, sampling was not necessary; the researcher had sufficient time to see every inpatient admitted for burn contracture reconstruction during that period. There were three plastic and reconstructive wards in the hospital; one male ward, one female ward and one paediatric ward. The researcher and interpreter visited each ward to review medical notes and ask the healthcare team to identify any potential participants. Doctors in the hospital had been briefed on the study and inclusion criteria; a few additional reconstructive patients were also identified by doctors on other wards and referred to the researcher.

Once a patient who appeared to meet the inclusion criteria was identified, the notes were read and a short assessment with the patient was conducted to confirm eligibility. The process documented above for acute burn participants was followed with regard to provision of study information and obtaining informed consent. Once a participant had consented, the researcher confirmed he/she was not due for pre-operative assessment or operation the following day; if not, the participant was interviewed the following day, or within 48 hours.

4.4.2.5 Outpatient sampling and recruitment

Potential eligible outpatients were referred to the researcher by the outpatient doctors who were aware of the study inclusion criteria. Due to limited numbers of outpatients who met the inclusion criteria, no sampling was required as all potential participants could be seen.

The researcher and translator first checked that the patient had time to participate, without jeopardy to any planned treatment or return journey home. Once this was confirmed, the translator and researcher proceeded with the study information and consent as detailed below. Once consent was obtained, the researcher and translator reviewed any medical documentation available and prepared the room for the interview and contracture measurement, affording the participant a short period of time between consent and participation.

4.4.2.6 Participant information and consent

The process of participant information and gaining informed consent was complex because of the language barrier. Initially, through the interpreter, the researcher informed each patient of the purposes of the study, clarified that participation was for research and not treatment purposes and that there was

no personal gain from their participation other than contribution to the study topic. The participant was informed in outline regarding what study participation would entail, namely an interview of approximately 45 minutes, measurement of the involved joints, photos of the joints and an audio record of the interview. It was made very clear that non-participation would not influence the patient's care or treatment in any way. If the patient and relative agreed to participation, the interpreter, in the presence of the researcher, informed the participant more fully on the study.

As the pilot study progressed, it was apparent that participants were not familiar with receiving written information. The hospital management strongly suggested that verbal communication with participants was preferable to written information. As there was considerable variation amongst the interpreters with respect to their fluency in English and knowledge of the research process, the researcher created a video in Bangla with the help of her local supervisor (a plastic surgeon) to ensure study information was consistently and clearly communicated in language understood by participants. At the end of the video, if the participant was willing to proceed, the interpreter guided the patient and relative through an oral version of the study information sheet (Appendix 10). If the patient agreed to participate after hearing the information, the translator provided the patient with a written copy of the consent form in Bangla (English version shown in Appendix 11). The interpreter also outlined the contents of the consent form verbally unless the patient was confident to read the form themselves. The consent form included explicit consent for photography of contractures and use of anonymised and non-identifiable photographs for research purposes. If in agreement, the participant signed the form (or provided a thumb print); the researcher and translator also signed and dated the form. Once informed

consent was obtained, the participant was interviewed within the next 48 hours, at a time convenient to the participant.

4.4.3 Data Collection

Three data collection methods were used:

- i) The focus group discussion was conducted with reconstructive inpatients
- ii) Data were collected on possible risk factors via semi-structured interviews with recruited participants in acute and reconstructive groups. These interview guides are provided in Appendices 7 and 8 respectively.
- iii) Identified joints at risk were measured for all participants

4.4.3.1 Location

The FGD was conducted in a private room within the hospital and involved only reconstructive patients for the reasons explained above. Outpatients were interviewed either in the Outpatient Department, on the ward or in a private room within the hospital when available. Inpatients were interviewed by their bed on the ward, or in a private room within the hospital when possible.

4.4.3.2 Interpretation

To enable communication and data collection, the researcher had to work closely with an interpreter. The interpreter was provided by the hospital and was not the same person throughout the pilot study; 7 interpreters were involved during the 14-day pilot study. Interpreters were either physiotherapists or doctors who worked within DMCH, but their levels of English proficiency varied. The interpreter was required for reading medical documentation, discussing logistic issues, identifying potential participants,

obtaining informed consent, and for all aspects of data collection whether by interview or FGD.

During the interviews, the researcher asked a question, the interpreter translated it for the participant and then interpreted the response to the researcher. If no clarification was required, the researcher moved to the next question. Word-for-word translation was not provided, rather the interpreter's understanding of the answer given. Participants often responded in a very factual manner and with few words. In such cases, the interpreter simply mirrored the participants words. If the participant did not understand the question, or the participant's answer was not clear and/or contraindicated previous information given, then the researcher, interpreter, participant +/- relative discussed the issue until meanings were understood and details were clear or consistent.

The researcher guided the recruitment process and was present throughout recruitment, participant information and consent for the study. The researcher asked all the questions of participants in the interviews and recorded all the data.

4.4.3.3 Relative or attendant involvement

In Bangladesh, the relatives of a patient are greatly involved in and often provide the majority of care while the patient is in hospital (Zaman, 2005). If the participant was female, it was deemed culturally appropriate to involve her attendant (if preferred and agreed by the patient) in the process of providing study information and gaining consent.

4.4.3.4 Focus group discussion (FGD)

It was initially intended that inclusion criteria for the reconstructive group would be applied to FGD participants, but once on site, there was only one

adult reconstructive inpatient available at the time planned for the FGD. To enable the FGD to go ahead as planned, and to trial the reconstructive interview guide, a decision (suggested and approved by the hospital management team) was made to include parents of children currently admitted for burn contracture release in the Focus Group. Sampling was not required, as all the paediatric inpatients with a contracture meeting the inclusion criteria were included in the FGD (n=6). For the purposes of the FGD, no joint measurements were necessary.

The process of informing FGD participants and gaining informed consent was followed as outlined above (Appendices 11 and 12). In addition, the interpreter explained what a FGD entailed, as none of the participants (or interpreters) were familiar with the technique. All the parents who participated in the FGD knew each other in advance of the group discussion, because they had all been admitted on the same ward, and many had been there for weeks prior to the FGD. The FGD was conducted by the researcher with assistance from the interpreter, in a private room within the hospital, and lasted 45 minutes. After a welcome and introduction was translated, the researcher asked questions according to the FGD guide (Appendix 15). Each question asked and all answers given by participants were translated for the researcher throughout the FGD. The FGD was recorded on two mobile devices.

4.4.3.5 Semi-structured interviews

Semi-structured interviews, using the interview guides developed (Appendices 7 and 8), were conducted with the selected acute and reconstructive participants.

Data from the semi-structured interviews were collected from medical notes, the participant, participant's relative or attendants and researcher observation. Where possible, data from each source was triangulated.

It was intended to input data during the interview into the ODK App held on the researcher's tablet. However, continuous evaluation of the interview guides and methods of data collection throughout the pilot resulted in changes being made to the method of interview and data collection, and the interview guide underwent three iterations during the pilot study. The process of evaluation and change is outlined in the section on key findings of the pilot study. The use of ODK for synchronous data entry at the point of interview was discontinued after just two participants because it became apparent that the answers being given by participants did not fit the pre-set categories programmed into ODK. For the next two participants, the researcher transitioned to a paper form, taking notes throughout the interview, and audio-recording the interview. It was soon recognised that using the audio-recording alone would reduce the barriers between researcher and participant and allow questions to follow the participant's story more intuitively; a prompt sheet was used to ensure all topics were covered during the interview. Data for all subsequent participants were collected in this manner. Data available obtained from medical notes was directly entered into ODK.

4.4.3.6 Measurement of joints at risk

On completion of the interview the researcher photographed the joints at risk of contracture. A third ODK form had been developed to collect measurement data (Appendix 9). However, use of this form was discontinued after only 2 participants because it was not user-friendly within the environment and some adaptations to the measurement protocol were also required.

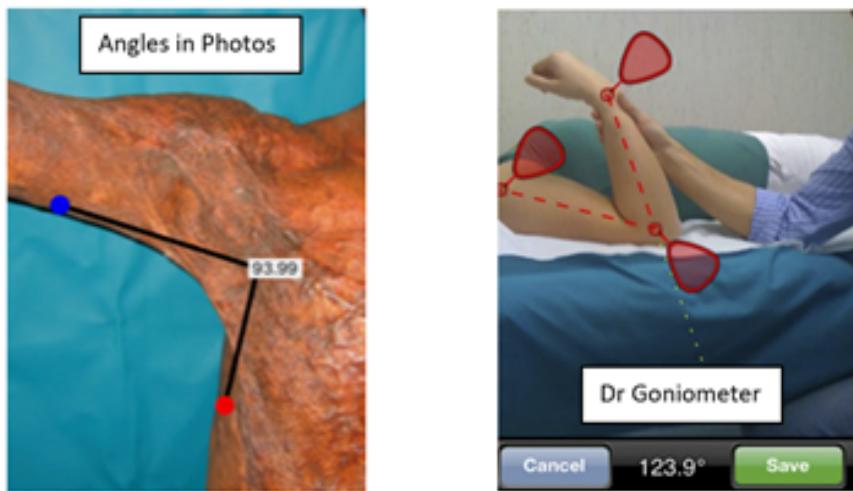
Contracture measurements were subsequently entered on a paper form and added to the end of the interview audio-recording by the researcher.

Measurement Protocol:

The protocol for measurement of each joint at risk included in the Pilot Study is shown in Appendix 13. In addition to the physical goniometer measurement described in the protocol, use of an app-based technology to capture a joint angle was tested. Two apps, called Dr Goniometer and Photo in Angles were used. The purpose of this trial was to compare the ease of App measurement compared to goniometer use in a challenging environment and to evaluate the accuracy of the App-measurement in a burn population. Evidence suggests that joint measurement apps can be as reliable as manual measurements (Ferriero et al., 2011; Milanese et al., 2014; Vercelli et al., 2017), although not yet tested in the burn population.

Both Apps measure ROM using the principles of goniometry, generated from photographs of the joint and associated limbs. Both Apps require human touch to place markers on the photograph from which the joint angle is generated. Dr Goniometer uses placement of a virtual goniometer, and Angles in Photos involves the placement of 3 dots as demonstrated in Figure 4-4. Angles in Photos is free of charge; Dr Goniometer was £11.99 to download and use the basic version.

Figure 4-4: Examples of joint measurement Apps



4.4.4 Data Management

In line with the ethical approval and hospital approvals the following principles were used for all data management:

- All data collected were anonymised; each participant was given a study number
- While in the hospital, devices used for research were kept in the personal possession of the researcher
- All data were recorded on an encrypted tablet. A separate phone for research purposes only was used for interview recordings and photographs; this was always password-protected and kept on the researcher's person
- Signed consent forms were retained by the researcher in a secured location in the hotel

Field internet speeds and security did not allow transfer of data from the tablet, laptop, or phones to the secure Swansea University server while in Bangladesh; data transfer was made from all devices on return to the UK. In the UK, data were kept on the researcher's private desktop computer, which was fully compliant with Swansea University data protection protocol.

4.4.5 Data Analysis

Continuous evaluation of the data collection process and forms was undertaken throughout the pilot study and adjustments made in situ as required. A full evaluation of the data collection process and tools was completed on return from the study site. All lessons learnt were incorporated into the planning of the final study. On return to Swansea University, the researcher transcribed the FGD and all the participant interviews verbatim to allow full review of the data and patient experiences.

A trial export of data from the ODK system, into Excel and then into SPSS was conducted, primarily to confirm that the data from ODK could be successfully exported via CSV files to SPSS for analyses. Once the data was in Excel and SPSS, the researcher cleaned the data and checked missing data. All contracture measurements were manually entered into Excel from documentation made in the field. As the main purpose of the pilot study was to develop the DCT tools and assess logistical issues, SPSS was only used in the pilot to confirm that export from ODK would be possible and to check presentation of data in SPSS. Excel was used to produce basic descriptive analyses from the pilot study.

4.4.6 Ethical Considerations

Ethical approval from Swansea University for clinician interviews and pilot study was awarded on 11th April 2019. (Appendix 5). Ethical approval from DMCH was awarded on-site on 9th May 2019 (Appendix 14).

4.5 RESULTS

4.5.1 Focus Group Discussion

The FGD was conducted on the first day of research with 7 parents who represented 6 children admitted for burn contracture release. Five parents were mothers and two were fathers.

The average age of the children was 6 years old (SD 2, Min – Max 4-9 years); 4 were male and 2 were female. On average, their burn injuries had occurred 3 years previously (SD 2, Min – Max, 1-7 years). Average age at the time of injury was 3 years (SD 3, Min – Max, 1-8 years). Three children had previous reconstructions for release of contractures of knees (n=2), shoulder (n=1) and neck (n=1). The children were admitted for release of contractures of neck (n=1), axilla (n=1), elbow (n=1), wrist (n=1), and ankle (n=2). It rapidly became clear that there would be insufficient time to cover all the planned questions in the FGD guide, therefore the planned FGD questions were reduced; the FGD guide is shown in Appendix 15.

The main findings from the FGD were:

- Patients and staff were not familiar with the concept of an FGD
- As no local facilitator with experience in FGD was available, the researcher had to lead the FGD, which limited the flow of discussion as translation after each point was required
- Four participants tended to dominate the conversation and there was limited discussion amongst participants. Participants tended to report answers directly to the interpreter/researcher rather than discuss issues as a group
- Participants were able to remember details of the injury and treatment received in impressive detail. Participants were familiar with terms

such as percentage burn, skin grafting, physiotherapy, pressure garments, and infection

- Participants did not have a Bangla word for contracture. Four participants had heard the English word ‘contracture’. Participants used a description rather than a word for a contracture, such as (translated) “shortage of skin”, “tension over the skin”, “stuck” and “bent”
- Most of the perceived reasons given for contracture development were related to delay in treatment, inability to follow treatment and incomplete treatment. Only one parent had known during the acute burn phase that a contracture could develop; she had heard about it from her husband

Subsequent comparison with data collection from the initial pilot semi-structured interviews demonstrated that the semi-structured interviews enabled more specific data to be collected on the selected potential risk factors. This may have been a consequence of longer individual participant interactions in interviews, which allowed a greater number of more focused questions to be asked. For this reason, the FGD method of data collection was not used in the final study. The FGD was useful for exploring participant perceptions on the reasons for contracture, but these could also be ascertained from semi-structured interviews.

4.5.2 Pilot Study Interviews

4.5.2.1 Participants

Twenty-one participants were included in the pilot study, comprising 12 acute patients and 9 reconstructive patients. All patients who were approached for the study were willing to participate.

All 12 acute participants were interviewed, photographed, and measured according to the contracture measurement protocol. There were only 3 adult reconstructive participants available during the pilot study period (2 outpatients and 1 inpatient). The remaining reconstructive participants were children (n=6), represented by their parents in the FGD. The departure from the planned inclusion criteria to include <18 years olds in the study was encouraged by the hospital management, to compensate for the lack of adult reconstructive in- and outpatients at the time of the pilot study. Since the pilot study was simply to test the process of participant understanding and the logistics of the measurement process, it was felt acceptable to include parents and children at this point.

The duration of the interview process (including joint measurement) was variable but took an average of 30 minutes/participant.

4.5.2.2 Demographic and burn factors

Table 4-4 shows the age, gender, location of residence and basic burn details of participants in both groups. There were similar numbers of males and females. Participants were young; average age was 23 years for the acute group and 11 years for the reconstructive group. The majority of the acute group were from rural areas, but 7/9 reconstructive participants were from urban areas.

In the acute group, the mean time since injury was 9 weeks (SD 4, range 4-26 weeks). The average time from injury for reconstructive participants was 4.5 years. One reconstructive participant reported only 6 weeks had passed since the time of injury, but this did not appear consistent with his contracture. As he was an outpatient, no medical notes were available to confirm the date of the acute injury. With this outlier removed, the most recent injury in the reconstructive group was 1 year previously and the oldest injury was 14 years

prior to interview. Only one participant (in the acute group) had any comorbidity (epilepsy).

Table 4-4: Demographics and basic burn details of pilot study participants

Feature		Acute Group	Reconstructive Group
Age at time of interview (years) (n=21)	Mean (SD) Min - Max	23.17 (7.27) 18-40	11.11 (7.57) 4-24
Gender (n=21)	Male Female	7 5	4 5
Location (n=20)	Rural Urban	7 4	2 7
Age at time of burn (years) (n=21)	Mean (SD) Min - Max	23.18 (7.27) 18-40	6.28 (6.82) 1-20
Time since injury (weeks) (n=21)	Mean (SD) Min - Max	9 (4) 4-26	232 (250) 6-728
Cause of Burn (n=21)	Flame Scald Electrical Contact	8 2 1 0	7 0 1 1
TBSA (n=17)	Mean (SD) Min - Max	21.38 (9.12) 9-34	15.44 (10.80) 5-40
Depth of Burn (n=21)	Partial Thickness Full Thickness	5 7	0 9

No burns were caused by chemical agents; the single contact burn was caused by hot ash. There were 4 intentional (homicidal) burns (3 in the acute group and 1 in the reconstructive group). TBSA of burn was not available for three participants (all in the reconstructive group).

4.5.2.3 Treatment Factors

Although twelve of the 21 participants had received some first aid, the first aid administered was not appropriate according to current standard international advice (Stiles & Goodwin, 2018). Four participants in the reconstructive group had received their acute burn care at DMCH. All 9 participants in the acute group had come directly to DMCH following the injury.

The main treatment factors for each group are shown in Table 4-5. Average time to first graft for participants having a skin graft was 9.75 weeks (n=6, SD 9.38); the earliest graft was at one week and the latest at 28 weeks. Two of 6 acute participants who had a splint were deemed to have had an effective splint based on direct observation by the researcher. One reconstructive participant had an effective pressure garment (arm sleeve).

Table 4-5: *Treatments received by pilot study participants*

Treatments		Acute Group	Reconstructive Group
ITU stay (n=21)	Yes	5	3
	No	7	6
Skin graft (n=21)	Yes	2	4
	No	10	4
Physiotherapy input (n=21)	Yes	3	1
	No	9	8
Splinted (n=21)	Yes	6	3
	No	6	6
Exercise	Yes	8	3
	No	4	6
Pressure garment (n=10)	Yes	0	2
	No		7
Counsellor (n=21)	Yes	0	0
	No	21	21
Follow Up (n=9)	Yes	n/a	3
	No	n/a	6

4.5.2.4 Contracture Outcomes

The 21 participants had 64 joints at risk, of which 54 were contracted, giving a contracture rate across all joints of 84%. Four participants in the reconstructive group had undergone previous reconstruction (2 knees, 1 shoulder and 1 neck); these joints were excluded from the analyses.

Most joints involved were in the upper limbs; the shoulder was most commonly at risk and had a very high contracture rate (96%). The contracture rate overall was very high; 50 of 58 upper limb joints at risk developed a

contracture (86%) and 4 of 6 lower limb joints at risk developed a contracture (67%). Table 4-6 shows the contracted joints by anatomical location.

Table 4-6: Anatomical distribution of included joints

Joint	Number of Joints at Risk of Contracture	Number of Joints Contracted	Contracture Rate %
Upper Limb			
Neck	7	4	57
Shoulder	26	25	96
Elbow	13	10	77
Wrist	12	11	92
TOTAL	58	50	86
Lower Limb			
Hip	2	1	50
Knee	2	1	50
Ankle	2	2	100
TOTAL	6	4	67
GRAND TOTAL	64	54	84

Even at this early stage of assessment, all participants in the acute group had at least one joint at risk which was contracted. Overall, 26/35 acute participant joints at risk had contractures, all of which were moderate (14/26) or severe (12/26). More than half the reconstructive patients (12/22) had a moderate or severe contracture after a mean of 4.5 years from injury. The relatively young age of the reconstructive group makes it hard to determine what the final adult outcome of these contractures would have been. Table 4-7 shows the severity of contracted joints in each group of participants (missing measurements due to patient being too unwell).

Table 4-7: Distribution of contracture severity in joints at risk

Group	Contracture Severity			
	None	Mild	Moderate	Severe
Acute (n=35 joints at risk measured)	9	0	14	12
Reconstructive (n=22 joints at risk measured)	5	5	4	8
TOTAL	14	5	18	20

The above gives an outline of some of the data collected, but the main findings from the pilot study related to the method and process of data collection in preparation for the final study, which are presented in the next section.

4.6 KEY FINDINGS FROM PILOT STUDY

The pilot was a huge learning opportunity, which significantly altered the method for the main study. Overall, there was very little change to the risk factors to be examined, but several key changes were made to the study population, in how the questions were worded and in the conduct of the research process, to better suit local conditions. The main issues encountered are described below.

4.6.1 Focus Group Discussion

As semi-structured interviews were a much more effective form of data collection and logically simpler than the FGD, it was determined that no further FGD would be conducted, and data collection would be entirely from semi-structured interview of participants.

4.6.2 Participants

Various problems were identified with the acute participant group:

- i) The research environment was chaotic due to the number and nature of inpatients, many of whom were unwell. There was a high noise level, no privacy and overcrowding
- ii) The researcher was unable to view the wounds under dressings (essential for identification of joints at risk) due to unplanned timing of dressing changes
- iii) It was not possible to measure contractures without dressings as at dressing time there were multiple patients in the area, a lack of space and no ability to position the patient, lack of privacy, patients were in

pain and there was also an infection risk. With dressings on, it was difficult to assess if limited ROM was due to dressings, pain, or other confounding factors. It was also difficult to accurately place the goniometer in the presence of dressings

- iv) Due to their recent injury, patients appeared vulnerable; many did not know what a contracture was (even if they had one) or the implications of having a contracture. It was felt that the acute patients had sufficient stresses without the additional burden of being recruited, interviewed and measured for the study
- v) Sampling was difficult due to limited documentation from which to assess inclusion without direct assessment of each potential participant

The reconstructive group also presented some problems:

- i) Medical notes for the acute injury were often not available
- ii) The researcher could not directly assess past treatment factors such as whether the participant had used a well-fitting splint
- iii) Potential recall bias/loss of memory of some aspects of treatment due to prolonged time between injury and assessment
- iv) Lack of availability of potential participants compared to the acute group (later found to be directly related to timing of pilot after Ramadan started, when elective patients are not admitted and are not willing to travel to outpatients)
- v) Difficulty in planning recruitment due to the lack of any formal follow-up system and unplanned admissions for reconstructive surgery

Despite these problems, the advantages associated with the reconstructive group were felt to outweigh the disadvantages. A decision was made to include only reconstructive participants in the final study, but to take account

of any upcoming national/religious festivals to increase potential reconstructive participants.

Several other strategies to increase the numbers of reconstructive patients were considered, such as changing the location for the final study to somewhere with greater predictability of reconstructive cases, including children as participants, including participants with previously reconstructed joints, or including inpatients with 'established' contractures. Although the numbers of paediatric outpatients and admissions exceeded those of adults, it was decided only to include adult participants in the final study because of the previously discussed impact of growth which could diminish or increase the impact of other risk factors.

The local hospital team at DMCH were optimistic that, provided holidays were avoided, enough reconstructive patients would be available for the final study, therefore no further action was taken. The existing inclusion criteria for reconstructive participants were not changed.

4.6.3 Quantitative vs Qualitative Data Collection

Experience with the interview guide demonstrated that some questions needed to be more open-ended with prompts, rather than seeking pre-categorised responses which had been built into ODK, as this led to inaccuracies during an evolving story and participants' lack of understanding of certain terms. Once questions were understood, participants were very brief and matter of fact in their responses.

It was initially hoped to extract qualitative information from reconstructive participants, but in the event, very little qualitative data could be obtained in the interviews. This was in part due to the lack of interview experience of the interpreter and the researcher being unable to assist because of the language

barrier. Additionally, Bangladeshi patients are not used to extensive interviews or discussing personal experiences in detail with health professionals and tended to provide short answers without supplementary explanation. This finding was consistent with the patient/healthcare professional relationship described by Zaman (2005). Although more qualitative explanatory information would have been helpful for discussion, the answers given could easily be converted to quantitative data, which was easier to manage at the data input and analyses stages because of the amount of information being gathered on so many topics.

It was also found that data collection was best suited to audio-recording rather than the planned synchronous entry to the ODK platform. Recording data allowed better interactions with participants than simultaneous entry on ODK, as the latter required the researcher's attention to be diverted away from the participant and the tablet was a distraction in the environment.

4.6.4 Interview Guide and Questions

Minimal changes were made to the risk factors included in the guide, but some changes were made to the order and method of extracting the information. Local input from the interpreter, the local supervisor and two local psychologists helped to optimise the language used for ease of understanding and create more appropriate categorisation of answers.

Use of the acute and reconstructive DCTs identified risk factors which needed further refinement and terms requiring better definition, for example what constituted 'appropriate' first aid or 'effective' splint use.

No changes were made in the risk factors to be examined apart from oedema and pain threshold. Oedema was excluded from the final study as acute participants were no longer involved and the presence of oedema at an earlier

stage was hard to determine in the reconstructive group. Pain threshold was also removed as patients could not understand this concept and it was difficult to quantify. Some supplementary questions were also deleted following the pilot study as they were not directly relevant to potential risk factors, including questions on distance and means of transport from each treatment stop and the opinion question “did anything make your contracture better or worse?”

Some potential risk factors were found to be difficult to elucidate accurately through interview and/or lacked meaning for participants, such as psychological well-being and activities of daily living (ADLs) or function. Validated measures for psychological aspects and function, such as the EQ5D were considered for use. However, they were not included due to the time required for completion, which would not be available during the interviews; these questions were therefore deleted.

Changes to the order of questions were also made as it was found to be advantageous to the flow of discussion to move participant opinion questions from the start of interview to the end and to start with demographic questions. A checklist of data to be collected was created to ensure no important questions were overlooked. Although fairly long (average 30 mins), the interviews were well tolerated by participants, therefore no major reduction in the number of questions posed was necessary.

4.6.5 Participant Opinion

Participants in the pilot study were asked for their opinions on how best to explore the topic and why they believed they had/had not developed a contracture. Participants were unable to comment on study design and did not contribute any new potential risk factors for burn contracture formation.

Often, the participant would simply respond “don’t know” or “due to burn” when asked why they thought they had developed a contracture.

4.6.6 Use of ODK

ODK was used to speed up and organise data, in part by the categorisation of potential responses. However, the categories pre-programmed into ODK did not fit well with participant answers, so capture of the full answer, with subsequent categorisation was deemed more suitable. For example, it was often found that participants had not had formal physiotherapy but did have splints or exercise prescribed by doctors rather than physiotherapists. Other categories were removed, such as category of income and type of work; it was considered more appropriate to record the raw data and categorise later.

ODK had been set up to capture the location of the burn at every aspect of every joint, but the details required were too time-consuming to collect this way, therefore the use of ODK for description of the burn was discarded. Instead, a chart was designed on which this researcher could sketch the area of scar and presence of any skin grafting (illustrated in Methods Chapter). ODK had also been programmed for joint measurement input, but this involved scrolling through multiple screens which was time-consuming. Joint measurement on ODK was discontinued and a paper measurement form was designed for use in the final study (shown in the Methods Chapter).

Although risk factors for the person and joint aspects would remain integrated for the interview, the data input for the final study was separated into two separate ODK templates for whole person and individual joint risk factors as this enabled export into two separate databases to simplify the different levels of analyses required.

4.6.7 Interpretation

It was evident from the pilot study that quality interpretation was crucial for the success of the research. There were several issues with interpretation during the pilot study:

- i) Lack of consistency of interpretation (7 interpreters over 14 days)
- ii) Very poor level of English proficiency in some interpretation
- iii) DMCH management did not wish to use external interpretation services, preferring to select their own interpreters; although clinicians, these interpreters had no experience in research methods
- iv) Due to the high volume of patients in DCMH, most doctor/patient interactions are very brief, therefore some interpreters found the prolonged interviewing of patients a new and challenging experience, as did participants
- v) Interpreters sometimes reported their own opinion rather than the patient's experience. This was noted as the researcher could understand some Bangla and observed participants' body language, signing and facial expressions, which sometimes suggested a different response from that given by the interpreter. If this occurred, the interpreter was asked to repeat the question and the response was discussed to ensure complete understanding by participant(s), interpreter, and researcher
- vi) Interpreters needed to fit the interpreter duties into their busy clinical workload (without additional payment) which was a potential disincentive
- vii) The interpreters were all physiotherapists or doctors working at DMCH, but not all worked in the burn unit, which could have biased their approach to the interview process and the answers given by participants, although no such bias was observed

Following the pilot study, the researcher met with DMCH management to suggest hiring interpreters who had experience in interview techniques and were familiar with research methods. As this was not possible, the optimal characteristics and skills of an interpreter and the importance of consistency were discussed to help inform the hospital's selection of interpreters for the final study. A training session on the principles of research which could be conducted with interpreters prior to the final study was also prepared.

The researcher was informed by local people (including the medical community and pilot participants) that there was no exact word for the English word 'contracture' in Bangla. However, as local doctors believed that participants would know the English word contracture, which they also used with patients in reference to a contracture, it was decided to use the word 'contracture' in interviews in the final study.

4.6.8 Local Support

As the interpreters might not know the DMCH or SHNIBPS environments, it would also be necessary to work closely with hospital management and clinical staff during the final study. An Associate Professor of Burn and Plastic Surgery had been designated as a volunteer to assist the researcher during the pilot as required; his on-the-ground assistance for the final study would be beneficial.

4.6.9 Importance of Relatives / Carers as Participants

The participation of relatives or carers in the interview process was initially considered optional for participant support. However, they were found to be a key source of information and it was determined that they should be included in the final study interviews unless the participant did not wish them present; this was especially valuable if they had been present during the acute injury and treatment phase. To this end, a few demographic questions for the

relative/carer were included in the final DCT and an expectation was set to include relatives wherever possible in the final data collection.

4.6.10 Contracture Measurement

The pilot study exposed the fact that the proposed methods of contracture assessment were not robust enough. As this was the key outcome measure for the project, revision before the final study was required. The App measurements did not appear to add value and were not felt to be accurate. The local physiotherapist was not always available and was not familiar with goniometry. Although the interpreters were medically trained, they were also not familiar with goniometry and were likely to introduce error rather than collect reliable information. Consequently, the plan to use a second assessor for measurement was discontinued and it was determined that only the researcher would measure contractures. The contracture measurement protocol was refined accordingly for the final study (described in Methods Chapter).

Photographs of contractures remained a valuable source of data and were continued. The paper form for joint measurement was adapted and finalised for the final study.

4.6.11 Recruitment

There was limited research experience or capacity available locally, and the concepts of research recruitment, information, consent, and debriefing were not familiar to the local team. Therefore, training was required, and efforts were made by this researcher to follow the requirements of Swansea University in these respects while adapting to local customs. For example, it was not considered appropriate to give written information to participants, as many were unable to read and appeared concerned by receiving large amounts of written information. Logistic factors precluded leaving time

between consent and participation for outpatients because of the limited time they could spend in the hospital, due to long journeys home and short OPD hours (8am-2pm).

The video used in the pilot study enabled more consistent transmission of participant information, but participants appeared to lack concentration when watching the video and preferred face-to-face communication. It was anticipated that with additional training and more consistent interpreters with greater English proficiency, effective participant information and demonstration of the measurement process could be achieved orally through interpreters in the final study.

Patients were keen to be involved and appeared to enjoy the opportunity to participate. Outpatient staff were very eager to increase recruitment to the study, therefore vigilance was required to ensure potential participants met the inclusion criteria and had time to participate without detriment to their journey home, access to meals or treatment.

The normal requirement for the offer of psychological support/debrief for research participants after interview was not feasible; no psychological or counselling services were available. It also appeared culturally unacceptable for participants to ask for such support; even offering help could be misunderstood. When asked, none of the pilot participants wanted psychological help. It was agreed by hospital management that details of a wellbeing NGO, with experience with burn survivors, could be given to participants at the end of the interview during the final study. The adaption of procedures for recruitment, informing, consenting, and debriefing for the final study are reported in the Methods Chapter.

4.6.12 Ethical Approval

This researcher was initially told by a senior member of the hospital management team that local ethical approval for the main study was not needed, but once on site for the pilot, it became apparent that a DMCH ethical approval system did exist. The process involved an application form, a small administrative fee and face-to-face contact with the head of the Ethics Committee of DMCH. This process could not be completed in advance of the final study, but once known to the researcher, could be prepared for and applied for in person on the first day of arrival.

4.6.13 Other Factors

4.6.13.1 Organisation

It became clear that a high level of personal organisation would be required due to the chaotic research environment, the amount of data to be collected, and the multiple interpreters involved. The researcher created improved data management systems for the final study, including a 'research' pack containing appropriate forms to be given to interpreters in advance. Forms for patient registration, consent, study information, contracture measurement, and topic checklists for semi-structured interviews were all printed in advance for use by the researcher and translators. Identification of key contacts on the ground was also important.

4.6.13.2 Missing data

Although the best source of information was the participant, efforts in the pilot study to try and follow the participant's story in a truly qualitative manner resulted in other questions being missed. In addition, some participants could not answer all the questions. Analysis of pilot data revealed that missing data

was a problem; the researcher developed a check list for the final study to decrease the percentage of missing data.

4.6.13.3 Study location

A departmental move from DMCH to The Sheikh Hassina National Institute for Burns and Plastic Surgery (SHNIBPS) was imminent at the time of the pilot study, although it was not clear if SHNIBPS would be open by the time of the final study. The researcher had to be as prepared as possible and ready to conduct the research in an unfamiliar environment. SHNIBPS is a new 500-bedded purpose-built unit for burns and plastic surgery, five minutes' walk by public road from DMCH. SHNIBPS is also predominately a Government Institution, but as with DMCH Burn Unit, limited private care is also available.

4.6.14 Summary and Conclusions

The experience of the pilot study confirmed that it was a vital stage in preparing for the main study, not only in terms of ensuring that the correct type of data could be collected but that procedures for data collection were suitable for participants and the local environment. The main changes made as a result of the pilot study are summarised in Table 4-8 below. The final version of the revised DCT and the procedures used for the main study are described in the next chapter.

In addition to the changes noted above, the pilot study confirmed that despite limitations, the patients were the best source of information. Participants were able to answer the questions and had better than anticipated understanding and recall of information required, even if the injury happened some time ago; relatives/carers helped with this. Participants often could report details, such as dates of skin grafts and TBSA, which agreed with the limited information in available medical notes. Medical notes were either not available or provided limited information. Physiotherapists did not document assessment or

intervention in notes and nurses wrote minimal information in separate books, which did not add to the aims of the study. All patients approached for enrolment to the study wanted to participate and did so enthusiastically.

Overall, despite the inherent limitations of a cross-sectional study, it was felt to be the design which best suited this environment. The list of risk factors explored in the pilot was comprehensive; although change in format and method of collection was required there were minimal changes to the risk factors examined and no new risk factors were identified.

Table 4-8: Changes made to study protocols after pilot study

Area of Concern	Decision
Focus group discussion	No further FGD, data collection through interview only
Participant recruitment	Due to problems assessing acute patients, only reconstructive patients to be included in final study. Final study to take account of national/religious holidays
Quantitative vs qualitative data	Data extracted from interview to be as qualitative as possible, but data entered to ODK in quantitative format
Risk Factors and interview Guide	Refinement of definitions, removal of questions not directly related to risk factors, changes in order of questions. Interview guides revised for final study (see Appendices 15,16 and 17)
Translation	Requested two regular translators with appropriate skills for duration final study. Prepared a training session on the principles of research to be conducted with the translators prior to the final study
Importance of relatives/carers in interviews	Value of relatives/carers recognised. To be included in interviews when possible, a few demographic questions for the relative/carer included
Contracture measurement	Single assessor only, app use discontinued, contracture measurement protocol further developed for final study (described in Methods Chapter)
Recruitment, informing, consent and debrief processes	Review of the recruitment, informing, consent and debrief procedures for the final study- described in Methods Chapter
Ethical approval	Unable to gain ethical approval in advance (due to local processes) but could organise for immediate action on arrival
ODK problems	Use audio recording for data collection from the patient, keep ODK use but input data extracted from audio record and other sources offsite. ODK format used in pilot revised and reordered in preparation for the final study. Data collection from joint measurements would not be collected in ODK but in paper form in a joint measurement table

Table 4-8: (continued)

Area of Concern	Decision
Organisational issues	Created improved data management systems for the final study, arrive with pre-printed forms available. Local Associate Professor to assist with logistics and participant recruitment for the final study
Missing data	Stopped synchronous data entry on ODK. Developed research check list for the final study to ensure all data would be collected (see Appendix 19). Also developed check list on data to collect from medical notes (Appendix 20)
Uncertainty re: imminent move of research location	Be as prepared as possible based on the pilot and prepare to conduct research in a new and unknown environment (SHNIBPS)
Participant numbers and data analysis	Sufficient participants required to enable complex risk factor analyses, final study numbers to be determined Final study analyses will be largely quantitative - aim for 60 participants

5 MAIN STUDY METHOD

5.1 INTRODUCTION

This chapter outlines the methods of the main study including the population studied, recruitment process, tools used, interview process and measurement procedures, together with an explanation of how the outcome measures (presence and severity of contracture) were calculated.

The aim of the final study was to collect data on exposures (risk factors for burn contracture formation) and outcomes (burn contracture presence and severity), using the interview guide and joint measurement protocol which were developed as described in the preceding chapters.

5.2 STUDY SAMPLE AND PARTICIPANT RECRUITMENT

The study population included any adult (≥ 18 years) inpatient or outpatient at DMCH or SHNIBPS, who met the inclusion criteria. As determined by the pilot, only reconstructive patients were included in the study. The aim was to recruit 60 participants during a 4-week field trip. Initially, joints at risk from all types of burns were included, including electrical burns. However, it became apparent that electrical burns were a very different and complex subgroup compared to other burn aetiologies due to the particularly high voltage nature of electrical burn injuries in Bangladesh (Islam et al., 2019) and their potential for causing extensive deep tissue damage without corresponding skin scarring (making retrospective assessment of severity difficult); electrical burns were subsequently excluded (see 5.4 and 6.1.1).

5.2.1 Inclusion Criteria

The inclusion criteria used for recruitment of participants were as follows:

- Participant admitted to DMCH/SHNIBPS for reconstruction of a burn contracture of at least one joint at risk,

OR

- Participant is an outpatient at DMCH/SHNIBPS with at least one joint at risk of burn contracture

AND

- Participant has at least one major joint (neck, shoulder, elbow, wrist, hip, knee, ankle) at risk of contracture. Minor joints excluded, even if contracted or at risk of contracture.

A joint at risk was defined as any observable significant scarring which met or crossed a joint line and was believed likely to result in a contracture. Additionally,

- The joint(s) at risk should not have undergone any previous surgical release, nor have had any loss of ROM prior to burn injury
- Participant and/or a relative could provide a full history of the injury and care from the time of burn to interview
- Participant consented to the study and had no cognitive, intellectual, or physical impairment affecting oral communication
- Contracture location allowed joint measurement without compromise to participant's privacy and dignity within the environment available
- Participant has the required time for recruitment, consent, and participation processes without detriment to their care or journey home
- For inpatients, medical notes should be available

5.2.2 Sampling of Study Population

Non-random convenience sampling was used for both outpatients and inpatients. All eligible patients attending DMCH/SHNIBPS during the study period were included.

5.2.3 Recruitment Process

5.2.3.1 Inpatients

Eligible patients were identified through daily ward visits to SHNIBPS and DMCH. The reason for admission was confirmed with the nurse-in-charge and medical notes were examined to confirm eligibility. If case-note information was insufficient, eligibility was confirmed through discussion with the patient.

The interpreter then confirmed patient willingness to proceed. An outline of the study was given, emphasising that the project was for research and not for treatment, that treatment would not be affected if they chose not to participate and that there was no financial or other gain to involvement in the study. If the patient agreed, an overview of what participation would entail was given. If the patient was still agreeable, the researcher was introduced and remained present throughout the discussion of the study information. Appendix 21 shows the content of the study information delivered verbally by the interpreter. If participant and attendant agreed to participate, a copy of the consent form was given to the patient in Bangla (Appendices 22 and 23 [English translation]). If the patient could read the form themselves, s/he was given time to do this, otherwise the interpreter explained the information to them verbally. The participant signed or thumb-printed the consent form, which was then dated and signed by interpreter and researcher. The participant was informed that the interview would take place within 48 hours, at a time that suited the patient and relative.

5.2.3.2 Outpatients

Some planning was possible with inpatients, but the daily numbers of eligible outpatient participants were unpredictable. A typed card listing the study inclusion criteria was placed in all outpatient rooms at both sites to facilitate

identification of eligible outpatients. The researcher and translator also visited the outpatient department every 2-3 days to check the card was in place and remind the outpatient doctors, clarify any issues, and answer any questions. The Associate Professor assigned to the study, or his team, also visited DMCH outpatients daily to remind staff of the study and inclusion criteria.

Once a potential outpatient participant was identified, the translator and researcher assessed his/her eligibility as quickly as possible, to prevent unnecessary patient waits. If a wait was unavoidable, the researcher and translator confirmed that the patient could wait to participate in the study, without any inconvenience to their care or journey home.

A brief overview of what was involved, and the amount of time required for participation was explained to the patient by the translator at the outset so that the patient's time was not wasted with the full information if they were unwilling or unable to participate. If the patient and relative agreed to participate, the researcher and translator gave fuller verbal details on the study, as outlined in Appendix 20. The contents of the consent form (Appendices 21 (English) and 22 (Bangla)) were also communicated verbally; if the patient and relative agreed to participate, the form was signed, or thumb printed by participant, translator, and researcher.

Whenever possible, participants were given a short period in the waiting room before the interview began, but occasionally, due to time constraints, the interview commenced immediately following consent.

5.3 PROCEDURE AND MATERIALS

5.3.1 Timing

Taking account of Bangladesh national and religious holidays, the main study took place over one month (14th October – 14th November 2019); the time was

limited by the duration of the visa issued. Research activity was conducted during the hours worked by hospital management and senior doctors (08:00 – 14:00) on 6 days a week, excluding Fridays.

5.3.2 Location

In addition to DMCH (450-500 inpatients daily), the new location SHNIBPS was partially open and had capacity for an additional 120 inpatients at the time of the final study. Over 160 burn/plastic surgery patients were seen between 08:00 and 14:00 daily across both sites during the study period, between approximately 60 outpatients attended SHNIBPS daily.

Interviews were conducted at SHNIBPS whenever possible; it provided a more conducive research environment than DMCH, being considerably quieter, less crowded and having private space for interviews and assessments. Only less mobile DMCH inpatients were interviewed at DMCH.

Interviews and measurement of joints at risk were conducted in a private room in the ward or outpatient department of SHNIBPS, or by the bedspace of an inpatient in DMCH.

5.3.3 Interpreters

The hospital management designated and scheduled one to two DCMH Physical Medicine Doctors to provide interpretation and accompany the researcher for three consecutive days at a time during the study. The researcher was not involved in the selection process for interpreters, who received no payment for their services.

The interpreters helped with cultural understanding and logistics, translating medical documentation, interpreting all communications between researcher and participant, confirming participant eligibility and willingness to

participate, obtaining informed consent, and assisting in completion of study paperwork as instructed.

To increase the consistency and effectiveness of translation and maintain the standards of the research, the researcher delivered a PowerPoint training session to each new set of interpreters. The training included:

- Purpose of the research and overall study design
- Logistics such as the locations of participant recruitment, interviews and assessments, and a general orientation to DMCH Burn Unit and SHNIBPS
- A list of tasks to be undertaken by the interpreter each day
- Recruitment, information and consent processes and associated documentation
- How to complete the paperwork required
- Basic research principles and interview techniques
- Basic introduction to joint measurement rationales and processes, how to help with joint measurements and instruct participants accordingly, and how to complete joint measurement forms

Interpreters were provided with a pack including a schedule of all interview questions, participant information and consent forms and the study inclusion criteria. Interpreters were given time to read the interview schedule and the information prepared to inform participants; key points were discussed between researcher and the interpreter, and the interpreter then role-played the delivery of the study information with the researcher acting as participant.

At the end of each day, the interpreter(s) and researcher shared feedback, to identify any procedural improvements needed and enhance the performance of both interpreter and researcher.

The researcher guided the recruitment process and was present for informing and obtaining consent from all participants. The researcher asked all the questions in the interviews and recorded all the data produced.

5.3.4 Further Local Assistance

Although the interpreters worked within DMCH, they were not familiar with the Burn Unit or SHNIBPS, therefore local departmental assistance from the Burns and Plastics team was required to optimise identification of potential participants.

The Associate Professor of Burns and Plastic Surgery who had been a key contact during the pilot study was assigned, in a voluntary capacity, to help the researcher with any logistical issues and with identification of potential participants. A brief planning meeting was held with the Associate Professor on most mornings, and a brief debrief took place at the end of most days.

5.3.5 Data Collection on Risk Factors

5.3.5.1 Interview process

Prior to commencing participant interview, the following details were confirmed:

- That the participant was entered onto the registration form which documented every stage of study participation including identification, eligibility, consent, and completion of the data collection
- That all paper copies of data collection forms were labelled with the participant's initials and study number and were ready for completion
- That all devices were ready to record data in the formats required
- That the participant had been informed, had consented, and met all the inclusion criteria

- That only the appropriate people were in the room (participant and relative(s), interpreter, and researcher) and that they were comfortably seated.
- That available medical documentation had been read by the researcher, entered directly into ODK, and/or been photographed
- That the researcher had identified participant's joints at risk of contracture and determined which joint-specific questions would be included in the interview

All available sources of information (participant, relative, researcher observations and medical documentation) were used to collect data according to the DCT. Where possible, the researcher triangulated data from different sources. If there was inconsistency between sources, available medical records on dates of admission and discharge, TBSA, burn depth, dates of skin grafting, and presence of inhalation injury or infection were favoured over participants' responses. For other inconsistencies between case notes and participant/relative's accounts, such as participant age or history prior to admission, the participant's account was usually accepted. On the advice of the local clinical team, further data verification was made by confirmation from family members; if the most appropriate family member was not present, they were contacted by telephone by the participant. This was only necessary on a very small number of occasions.

Although the interview followed the form and content of the interview guide, the flow of the interview was dictated by the storytelling of the participant, which meant the topics were not always covered in the same order. If subsequent answers conflicted with previously reported information, the researcher reverted to the topic and clarified the information. To reduce the occurrence of missed data, a checklist was used (Appendix 19). Only relevant

questions were asked; for example, if a participant had not had any skin grafting then no further questions on skin grafting were asked.

To enable all attention to be focussed on the participant and optimise the flow and content of the interview, each interview was recorded on a mobile device. Notes were generally not made during the interview; the audio recording was the key source of data capture.

The interview process, including assessment of joints at risk, was expected to take 30-60 minutes but would depend on the number of joints at risk, the extent of treatment, recall of the participant and relative(s) and their willingness to communicate.

Interpretation of the Interview

During interviews, each question was asked by the researcher, translated by the interpreter, then the response was interpreted back to the researcher; if no clarification was required, the next question was asked. Word-for-word interpretation was not always provided, rather the interpreter's version of the answer to the question was given. Participants often responded in a very factual manner and with few words, in which case, interpretation was verbatim. If the participant did not understand the question, or the participant's answer was unclear and/or contraindicated previous information given then the researcher, interpreter, participant +/- the relative discussed the issue until meanings were understood and details were clear and consistent.

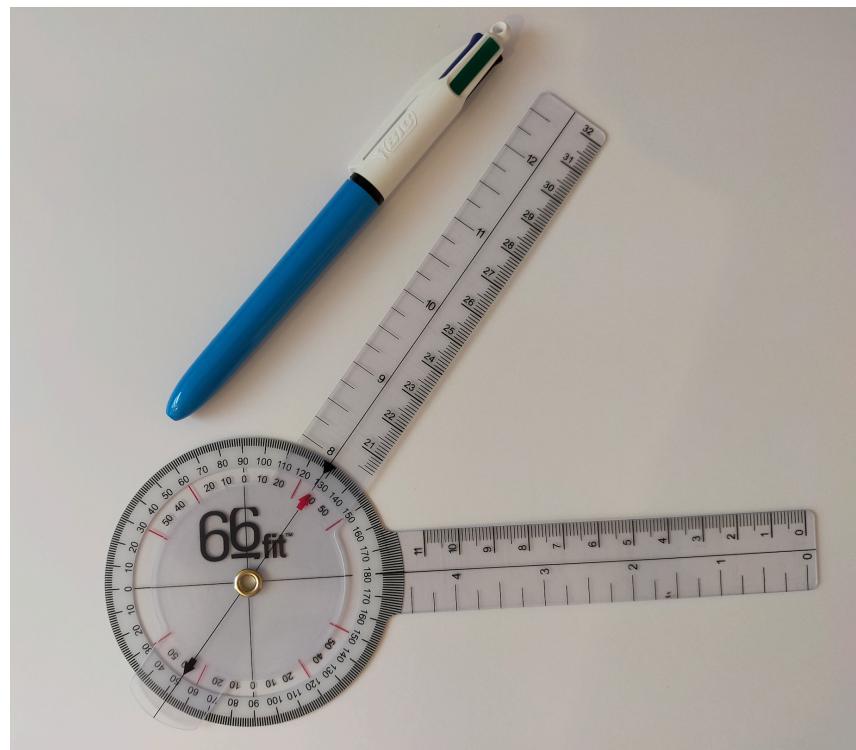
5.3.6 Data Collection on Joints at Risk of Contracture

Following interview, the participant was reminded that their joints would now be measured and photographed. Verbal consent to proceed was reaffirmed.

5.3.6.1 Measurement of joints at risk

A laterally placed transparent 8-inch 66Fit goniometer, was used for all goniometer measurement (Figure 5-1). Goniometer placement and participant positioning is shown in Table 5-1.

Figure 5-1: Goniometer used for joint measurement



Participants were given clear explanation and demonstration on how to move their joints for measurement. The participant was asked if she/he accepted the presence of the interpreter for the measurement and whether they preferred their relative be present or not. If the interpreter was not permitted to remain, the researcher managed measurements with sign language after prior explanation by the interpreter. Participant clothing was removed only to the extent required to accurately measure the contracture.

Table 5-1: Participant positioning and goniometer placement for joint measurement

Joint	Movement	Position	Placement of Goniometer
Neck	Extension	Seated	Axis: External auditory meatus Proximal Arm: Parallel to the ground Distal Arm: Base of the nares
Shoulder	Flexion	Supine	Axis: Lateral aspect of greater tubercle Proximal Arm: Parallel to mid axillary line of the thorax Distal Arm: Lateral midline of the humerus
	Abduction	Supine	Axis: Anterior aspect of acromion Proximal Arm: Aligned to midline of sternum Distal Arm: Anterior midline of the humerus
Elbow	Flexion and Extension	Supine	Axis: Lateral epicondyle of the humerus Proximal Arm: Lateral midline of the humerus, acromion as a marker Distal Arm: Lateral midline of the radius, radial styloid process as a marker
Wrist	Flexion and Extension	Seated, elbow flexed	Axis: lateral aspect of the wrist, over triquetrum Proximal Arm: lateral midline of ulna, target olecranon and ulnar styloid process Distal Arm: lateral midline of the 5 th metacarpal
Hip	Abduction	Supine	Axis: Anterior superior iliac spine Proximal Arm: Aligned horizontally to the contralateral anterior superior iliac spine Distal Arm: Anterior midline of femur
	Extension	Prone	Axis: Lateral aspect of hip joint, target great trochanter Proximal Arm: Lateral midline of pelvis Distal Arm: Lateral midline of femur
Knee	Flexion and Extension	Supine	Axis: Lateral condyle of the femur Proximal Arm: Lateral midline of femur Distal Arm: Lateral midline of the fibula
Ankle	Dorsiflexion And Plantarflexion	Seated	Axis: Lateral aspect of lateral malleolus Proximal Arm: Lateral midline of the fibula Distal Arm: Lateral aspect of the 5 th metatarsal

From the assigned starting position (Table 5-1), the participant was asked to make the first movement for measurement of the joint in question. This was an active movement performed solely by the participant, who was encouraged to move as far as possible through the relevant range. This movement was measured with the goniometer; if the ROM was clearly equal to or greater than the normal reference value for that joint and plane, full range of movement (FROM) was documented on the contracture chart (Figure 5-2) and no further measurements were taken.

Figure 5-2: Example of completed contracture chart

Study No <u>0012 MK</u>		Contracture Measurement Chart										Date <u>21/10/19</u>
Joint	Contracture	Other	Risk	Recon	Movement	ACT1	ACT2	ACT3	PAS1	PAS2	PAS3	
Neck	Flex	Intert	✓	X	Extension	40	43	44	50	50	50	Left shoulder + 11cm
	Ext			X	Flexion	FROM			FROM			
RIGHT Shoulder	Flex		✓	X	Flexion	FROM			FROM			
	Abd				Abduction	FROM			FROM			
LEFT Shoulder	Flex				Flexion				FROM			
	Abd				Abduction							
RIGHT Elbow	Flex				Extension							
	Ext				Flexion							
LEFT Elbow	Flex				Extension							
	Ext				Flexion							
RIGHT Wrist	Flex	Www	✓	X	Extension	FROM						
	Ext				Flexion	FROM						
LEFT Wrist	Flex		✓	X	Extension	FROM						
	Ext				Flexion	FROM						
RIGHT Hip	Flex				Extension							
	Add				Abduction							
LEFT Hip	Flex				Extension							
	Add				Abduction							
RIGHT Knee	Flex				Extension							
	Ext				Flexion							
LEFT Knee	Flex				Extension							
	Ext				Flexion							
RIGHT Ankle	Plantarflex				Dorsiflexion							
	Dorsiflex				Plantarflexion							
LEFT Ankle	Plantarflex				Dorsiflexion							
	Dorsiflex				Plantarflexion							

severe banding at neck → ↓① not + ② SF but less impact on ext.

① not FROM due to ② SF contracture (ear to acromian)

③ not FROM due to ④ not acromian (ear to shoulder)

If FROM was not achieved, the participant was asked to return to the starting position and repeat the same process twice more.

Once the three active movements were complete, three passive movements of the same movement were measured. The researcher moved the participant's joint through the same movement without assistance from the participant.

From clinical experience, the researcher could feel the full extent of movement possible, and the joint was taken to its maximum limit. Once at the maximum extent of passive movement, the interpreter held the position while the researcher measured the range. If the interpreter was not present the researcher held the position and completed the measurement. Passive range measurement was repeated three times. This process was repeated for each movement at each joint at risk. Only the passive movement measurements were used for subsequent outcome analyses.

5.3.6.2 Documentation of measurements of joints at risk

Joint Measurement Form

Prior to measurement, all joints, and movements to be measured were highlighted on the form to facilitate correct documentation by the interpreter (Figure 5-2).

Each goniometer measurement taken was reported by the researcher to the translator who entered the value directly into the joint measurement form. The margins of the form were used for notes as required.

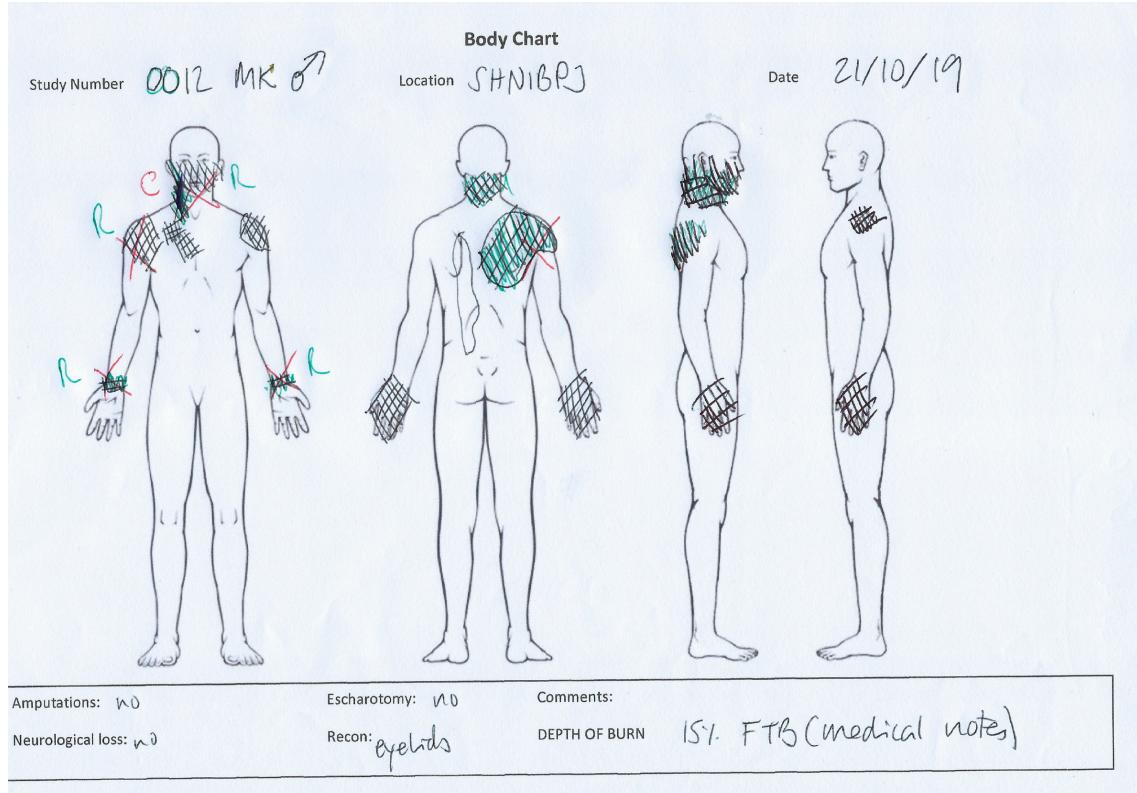
Measurements were also recorded on the audio recording. If the interpreter was not present, measurements were audio recorded and transcribed to the joint measurement form later. A qualitative description of the joint(s) at risk was also recorded, which augmented documentation of joints at risk and contractures; this was later used to cross-check other documented descriptions of joints.

Body chart (Figure 5-3)

A body chart was completed for every participant, showing all areas of visible scarring and any marks such as pigment change indicating skin was burned but not scarred. The extent of the burn sketched on the chart was important for estimation of TBSA, to compare with participant report or medical

documentation and to calculate TBSA category if TBSA was otherwise unknown. Every joint at risk and its contracture status were marked on the form, along with scar bands and skin grafts. The presence of any amputation, escharotomy, neuropathy or reconstructed joint was also documented. Figure 5-3 shows an example of a completed Body Chart.

Figure 5-3: Example of completed body chart



Photography

Photographs were taken of every joint included in the study, in order to triangulate visual observation with documented joints at risk and the presence and severity of contracture. Calculated contracture outcomes were checked clinically by cross-reference to the photographs. Consent for photography was explicit in the consent form and was verbally confirmed with the patient and relative before photographs were taken. Photographs were taken after interview, either before or after measurement of joints at risk. Composition of photographs was designed to best demonstrate contracture severity and

illustrate the maximum range of movements available. All photographs were taken on a mobile device used only for photographs.

5.3.6.3 The role of ODK in data collection

The interview recording was replayed offsite, and data entered directly into the ODK forms, housed on the tablet. Written notes were also made for each participant from the interview recording. The forms for data entry are illustrated in Appendices 17 and 18. ODK was programmed to enable categorisation of data, but definition of variables was an iterative process as the number of and variations in participant responses expanded. As the process evolved, a record was made of decisions taken on categorisation, to improve data consistency; these decisions are documented in Appendix 24. All ODK data was later adjusted according to the final decisions on categorisation.

5.3.6.4 Participant Debrief

After the interview, participants were asked if they had any questions. Enquiry was made into how it felt to recount their story and whether they had ever spoken to anyone about how the injury had affected them. Participants were asked if they felt they required any support to deal with any feelings that they had about their injury. If there was any indication that support was required, the participant was given a contact card for a local mental wellbeing charity, Innovation for Wellbeing Foundation, which had been approved by hospital management. Although was a general mental health charity, some staff had experience in burn-specific psychosocial support. It was emphasised that this NGO support was for psychosocial issues only and not for medical or financial help.

After the interview and joint measurements, all participants were offered a snack as a token of thanks. Selected outpatients were also offered 500 BD Taka

(equivalent to £4.50) to help cover travel and outpatient registration costs. Decisions on who should receive payment were based on participant poverty and distances travelled and were made solely by the medical team and interpreter only after interviews were completed.

5.4 DATA MANAGEMENT

Data management in the field included:

1. Creation of an electronic folder on the research laptop for each participant, containing scanned copies of all paper forms (consent, body chart, contracture measurement chart), photographs of the participant's joints at risk, copies of medical documentation and the audio file of the participant's interview
2. Typed notes of interview recordings and researcher observations, so that data from interviews were available in text form as well as ODK or audio
3. Completed ODK forms for each participant, containing data entered from semi-structured interviews
4. Typed notes of decisions made on categorisation of data during ODK entry to ensure consistency of input across all participants
5. A checklist to monitor progress through the data management scheme outlined for each participant

On return to the UK, data from ODK were exported to SPSS Version 26. Data from joint measurement forms was entered manually into Excel.

Data verification included:

1. Replaying all interview recordings and verifying field notes made on each participant with augmentation as required
2. Cross-checking audio and field notes against SPSS data. This process was repeated three months later, before data analysis commenced

3. Verification of the body chart, joint measurement form and SPSS data for joints involved, joints contracted, risk factors and measurements against photographs of joints at risk
4. Application of final categorisation of variables consistently for all participants. Appendix 24 shows the definitions and categories used
5. Data cleaning, during which missing or conflicting data were identified and corrected wherever possible.

Eight participants were subsequently excluded at the data cleaning phase. The reasons for ineligibility were previous reconstruction of the only included joint (2) and electrical burns (6). The latter group were ultimately excluded because electrical burns i) may have no residual skin scarring despite extensive deep tissue damage, ii) may have accompanying nerve damage which contributes to contracture formation iii) may have had acute stage reconstruction (flap surgery) due to the severe nature of electrical burns in this setting.

5.4.1 Data Security

In the field, all forms of data, apart from consent forms, were anonymised and identified only by study number and participant initials. All devices used for data or photographs were password protected. ODK data were also encrypted. All devices were held by the researcher, locked in a cabinet, or kept securely in the hotel. Data from devices were uploaded daily to the research laptop, which was password-protected and kept securely in the hotel.

On return to the UK, all data were uploaded to the secure and encrypted Swansea University server and to the researcher's private, password-protected desktop PC. Paper copies were kept in a locked cupboard within the department at Swansea University.

5.5 DATA ANALYSIS

5.5.1 Measuring Loss of Movement

ROM measurements were used to generate three distinct variables which served as metrics of the scale and severity of contracture. Potential risk factors were analysed against these the following outcomes:

- i. Presence or absence of contracture at a joint at risk
- ii. Severity of contracture (categorical)
- iii. Loss of Movement

5.5.1.1 Contracture Present or Absent

If the mean ROM calculated from 3 passive movements for the included plane of movement, measured with a goniometer, was equal to the reference normal ROM, the joint was defined as not contracted. Any difference between the mean of the 3 passive movements and the reference normal ROM was defined as a contracture.

5.5.1.2 Severity of contracture

If ROM of the measured planes were not full, the mean of the 3 passive movements was used to determine the severity of the contracture by the calculation of BCSC and LMS, as described below:

i) The Burn Contracture Severity Classification (BCSC)

BCSC was determined according to how much normal ROM was lost. Contractures were classified as none/mild/moderate/severe for no loss, up to 1/3 loss, from 1/3- 2/3 loss and >2/3 loss respectively (Schneider et al., 2006), Table 5-2. The plane of movement at the included joint with the greatest loss was taken to represent the severity of that joint. Formulae were created in the database to categorise each joint according to the appropriate BCSC. This was a categorical scale.

Table 5-2: FROM values and BCSC contracture severity categories

Joint Movement		Expected Full ROM (Degrees)	Degrees of ROM and Contracture Severity		
			Mild	Moderate	Severe
Neck	Extension	75	50-74	25-49	<25
Shoulder	Flexion	180	120-179	60-119	<60
	Abduction	180	120-179	60-119	<60
Elbow	Flexion	140	93-139	46-92	<46
	Extension	0	-1 to -45	-46 to -92	-93 to -140
Wrist	Flexion	60	40-59	20-39	<20
	Extension	60	40-59	20-39	<20
Hip	Extension	30	20-29	10-19	<19
	Abduction	40	26-39	13-25	<13
Knee	Flexion	150	100-149	50-99	<50
	Extension	0	-1 to -49	-50 to -99	-100 to -150
Ankle	Dorsiflexion	20	13-19	6-12	<12
	Plantarflexion	40	26-39	13-25	<13

i) Loss of Movement Score (LMS)

LMS is a continuous variable, calculated by expressing the actual loss of ROM in degrees as a proportion of expected FROM. The mean of the two planes of movement measured at each joint (other than one plane for the neck) represented the loss of movement at that joint. The normal ranges of movement for each joint used are shown in Table 5-2. Therefore, if an elbow (normal range 140 degrees) had only 100 degrees extension i.e., lacked 40 degrees of FROM, the calculation for LMS would be $40/140 \times 100 = 28.6\%$ loss of movement, LMS = 0.29 or 29%. Formulae were created in the database to calculate the LMS.

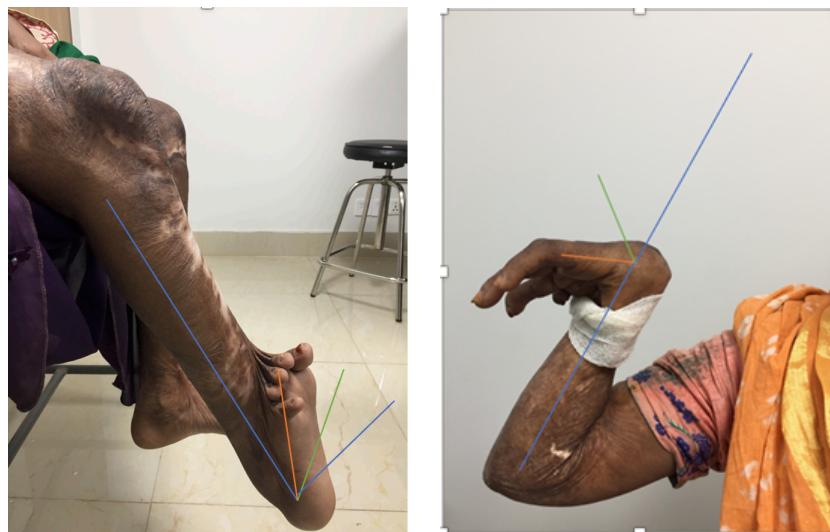
5.5.2 Measurement Difficulties

All contracture severity outcomes assumed a neutral (i.e., 0 degrees) starting position and that any movement is initiated from the neutral position. However, some participants who had severe contractures could not even reach the neutral position and any available movement was technically

outside the normal range. Therefore, for very severe contractures where the movement measured was outside the normal range of movement at that joint, that participant was classified as 100% loss for LMSj or LMSp and as 'severe' for BCSCj or BCSCp.

Examples of such severe contractures are shown in Figure 5-3. The blue line represents correct placement of the goniometer, the green line demonstrates normal FROM for the measured movement and the orange line indicates actual ROM, demonstrating that the measured range is outside the normal range.

Figure 5-3: Example of measurement challenges with severe contractures



5.5.3 Units of Analysis: Person and Joint

As described in Chapter 4.3.1.2, some risk factors are more appropriately examined at whole person rather than joint level. It was therefore necessary to determine an outcome for the whole person as well as individual joints, so that evaluation of whole person risk factors took account of the joint outcomes at all joints at risk. No whole person severity outcomes have been described previously. For BCSC, the worst contracture severity was taken to represent the whole person. However, for LMSp, all joints were included; the sum of the

mean proportional loss of movement at every joint was divided by the total number of joints at risk, giving a mean whole person LMS using the formula

$$\frac{\text{Sum of mean loss of movement in every joint at risk}}{\text{Number of joints at risk}}.$$

This resulted in a total of 4 potential outcomes (BCSCp, BCSCj, LMSp and LMSj) (Table 5-3).

Table 5-3: Person and joint level severity outcomes

	Burn Contracture Severity Classification	Loss of Movement Score
Person	BCSCp Each participant was categorised by their worst contracture Example: Participants with 4 joints at risk, one with no contracture, one with mild, one moderate and one severe, would be assigned to the severe group	LMSp Total of proportional losses of ROM at all joints at risk divided by number of joints at risk Example: 4 joints at risk with proportional losses of ROM of 0.66, 0.35, 0.11 and 0.67. Cumulative total is divided by the number of joints at risk i.e., $1.79/4 = 0.45$ or 45% loss of movement across all joints at risk.
Joint	BCSCj BCSC category of an individual joint Example: 4 joints at risk, one with no contracture, one with mild, one moderate and one severe – each would be classified separately	LMSj Degrees of movement loss expressed as a proportion of FROM for each individual joint Example: A wrist joint with normal FROM of 60 degrees has lost 20 degrees; this joint is calculated to have lost 0.33 or 33% of movement

5.5.4 Statistical Analysis

The data was analysed in SPSS Version 26 using a 5% level of significance. P-values were reported to 2 decimal places with the threshold interpreted strictly with p-values of 0.05 not considered to reach statistical significance.

Due to the small sample size and the distribution of the primary outcome variables the decision was taken to rely on robust statistical methods. As such the majority of the methods used were non-parametric.

5.5.4.1 Descriptive Statistics

All variables and outcomes at the person and joint level were described using appropriate descriptive statistics and graphs where appropriate. Categorical risk factors and outcomes were presented as simple counts. Continuous variables were expressed as mean and standard deviation or median and interquartile range; minimum and maximum values were also reported.

5.5.4.2 Risk Factor Analysis

The risk factor analysis was performed at both patient and joint level. At patient level there were no hierarchical effects to consider but for joint level analysis this was a potential issue. However, the small sample size meant that the use of any hierarchical methods was entirely unjustified and so it remains a potential, but unavoidable, shortcoming of that part of the analysis. Identical methods were therefore used for both parts of the analysis.

The three outcome measures were the presence of contracture (binary), burn severity (categorical) and loss of movement (continuous).

For presence of contracture two methods were used. Where the independent variable was categorical the Chi-Square Test of Association was used and, when appropriate the Standardized Residual was calculated. Since the expected cell counts were frequently low, the asymptotic p-values could be considered unreliable, so the Exact p-values were requested instead. Where the independent variable was continuous the categories of the outcome variable were considered as independent samples and the Mann-Whitney Test was used to detect differences in the level of the predictor.

For the categorical measurement of the severity of burns (BCSC) the same methods were used although Kruskal-Wallis was used in preference to Mann-Whitney due to the larger number of outcome categories.

Continuous data were tested for normality using Shapiro Wilks Test to ensure that appropriate parametric or non-parametric tests were used. Depending on distribution of data, Spearman's Correlation or Pearson's were used for continuous risk factors such as age and for the continuous contracture outcome (LMS). Kruskal Wallis, One Way Anova, Mann Whitney or T-Tests were used in comparing categorical and continuous variables depending on the number of groups and whether parametric (some joint level data) or non-parametric tests (all person level analyses) were most appropriate.

5.6 ETHICAL APPROVAL

Ethical approval for the main study was granted by Swansea University (Appendix 25). Written permission for the study was given by SHNIBPS/DMCH (Appendix 26). Formal permission and documentation to conduct the final study was granted by the Bangladesh Ministry of Health (Appendix 27 in Bangla, Appendix 28 in English). Ethical approval from DMCH/SHNIBPS was also granted (Appendix 29).

6 RESULTS I: DESCRIPTIVE ANALYSES OF SUBJECTS AND JOINTS

This chapter presents the descriptive analyses for the study population and joints studied.

6.1 OVERVIEW OF STUDY POPULATION

6.1.1 Interview Process

Fifty-six participants were interviewed. Eight were subsequently excluded at the data cleaning phase. The reasons for ineligibility were previous reconstruction of the only included joint (2) and electrical burns (6); all of the latter group had undergone reconstructive flap surgery during the acute phase or had accompanying nerve damage.

Thirteen translators were involved over the study period, most of whom were assigned to assist for 3 days at a time. The number of interviews conducted by each translator ranged from 1-7. Average duration of interview was 43 minutes (range 20-60 minutes, SD 11). Unexpectedly, two interviews were conducted in English because these participants (both private patients) were fluent in English. All other interviews were conducted in Bangla, with interpretation.

Most participants (37/48) were interviewed in the outpatient department at SHNIBPS. Participants attended outpatients for advice on surgical reconstruction for their contractures (37/48), ulcers (3) sinus (1) or scar discomfort (1). Six participants had non-specific concerns.

All included inpatients had been admitted for contracture release. Only 4/48 participants had undergone previous reconstructive surgery on a total of 8 joints; these reconstructed joints were excluded from the study.

Due to very sparse medical documentation, the main source of data was the participant/family. Information provided through interview was given entirely by the participant him/herself (n=17), or with minimal input from an accompanying person, who was either a close relative (n=15) or in 1 case the village doctor. In 15 cases the information was provided mainly or entirely by the accompanying relative.

Medical notes on acute burn care were available for only 10/48 participants; most notes were incomplete and contained only minimal information. There was no medical documentation for 23/48 participants.

Operationalisation of risk factors described below are listed fully in Appendix 24.

6.1.2 Demographic Data

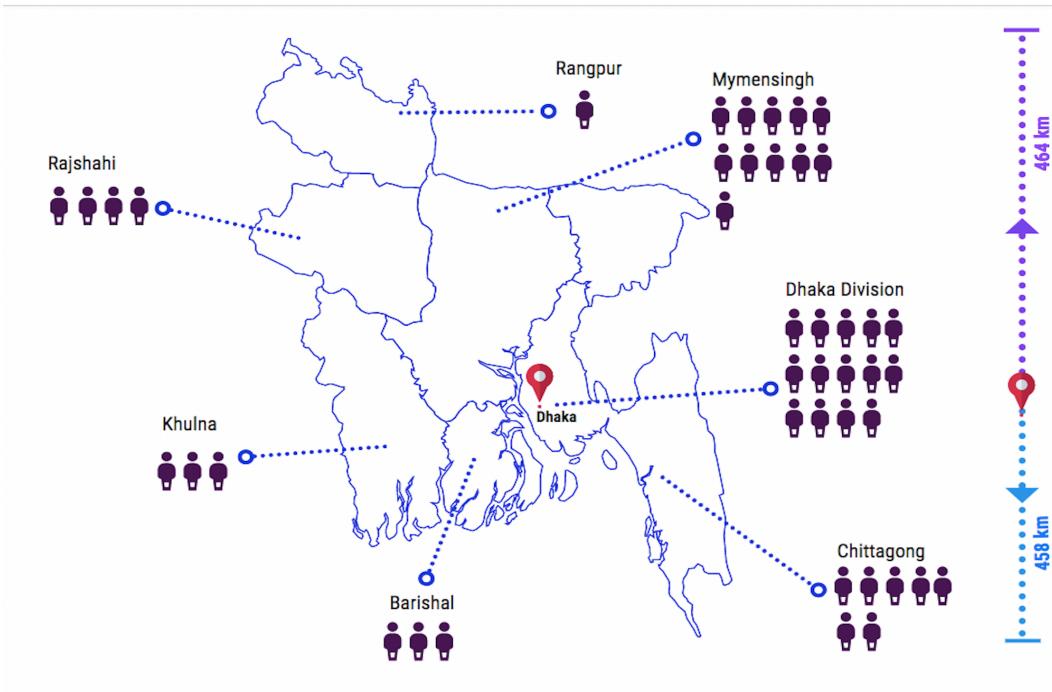
All 48 participants were of Bangladeshi ethnicity. As there was no variation in ethnicity, there is no further reference to ethnicity in the results. Twenty-three participants were female and 25 were male. The average age of participants at interview was 26 years (SD 8.19 years). The youngest participant was 18 years old and the oldest 53 years.

Residence data was collected by the type of area (rural, urban, semi urban) as reported by the participant, and by the Region and District in which the participant resided at the time of burn. Every region in Bangladesh was represented by at least 1 participant (Figure 6-1).

Seventeen participants were from rural areas, 10 were from semi-urban areas and 11 were from urban areas. Nineteen participants came from Dhaka Division, in which the study was conducted.

Many participants travelled long distances to reach DMCH/SHNIBPS (median 110 kms, IQ=161, Min, Max 1-400 kms). Travel time as well as distance was considered important because of high levels of congestion in and around Dhaka, which can result in long travel times despite relatively short distances; average journey travel time was 3.89 hours (median = 4, IQ = 3.5, Min, Max 1-12 hours). Travel time reported (in kms and hours) represents a single journey only (home to hospital).

Figure 6-1: Map of the Regions in Bangladesh showing origin of participants



Most participants were not married at the time of interview or at the time of the burn. Of those who were or had been married, 3 had no children, 14 had 1 child and 7 had 2-4 children.

6.1.3 Socio-Economic Data

6.1.3.1 Literacy and educational level

If the participant reported that they could read and write, they were classified as literate. Ten participants were illiterate.

The levels of education to which the participants studied are displayed in Table 6-1. 'Incomplete' levels classify participants who started but did not complete that level of education. The most frequently reported level of education was secondary (18/48). Eleven participants were students at the time of interview. Six participants had no education and 12 had no more than primary level education. Higher education (Honours and Masters) had been completed by 11 participants. Three participants received their education from a Madrassa, and the remainder from Bengali Medium schools.

6.1.3.2 Occupation

The majority of participants were unemployed (26/48); housewives and students were included in this group (Table 6-1). Only occupation at the time of interview was recorded, not at the time of burn. However, if the participant had a different job prior to the burn injury, this information was frequently offered by the participant during interview. Most machine operators worked in textiles. Elementary occupations included street-food sellers and farmers. Only two participants had managerial or professional occupations; both were private patients.

Table 6-1: Education and Occupation of Participants

Variable		N
Level of Education (n=47)	None	6
	Primary incomplete/complete	11/1
	Secondary incomplete/complete	14/4
	Honours	6
	Masters	5
Occupation (n=48)	Managerial & Professional	2
	Technical	3
	Skilled	0
	Machine operators	7
	Elementary	10
	Unemployed/homemaker/student	26

6.1.3.3 Household income

Average monthly household income (accumulated income of all those living in the household) was only available from 42/48 participants. The average monthly income was 19,273 BDT (SD 20,498), equivalent to £170 per month². Four outliers were noted. The 2 participants who received private healthcare had considerably higher monthly incomes (70,000 BDT/month and 120,000 BDT/month, equivalent to £619 and £1,061 respectively). Another (who received care overseas) had a monthly salary of 50,000 BDT/month (equivalent to £442/month). The final outlier had the highest income of participants treated in the Bangladeshi Government system. The participant's father was a headmaster, earning 30,000 BDT/month (equivalent to £265). With exclusion of the two participants who received private care, the mean monthly income was 13,466 BDT, equivalent to £119/ month.

6.1.4 Burn Injury Factors

6.1.4.1 Age at burn

The median age of participants at the time of burn was 21 years (range 1-49 years). The longest interval from burn injury was 37.5 years, and the most recent burn was 7 months old (median 2.5 years, IQ 11 years). Twenty-eight participants sustained their burn injuries in adulthood. Most of those who sustained their burns in childhood were injured in the first five years of life (11/20).

² <https://www.xe.com/currencyconverter/convert/?Amount=300%2C000&From=BDT&To=GBP>
accessed 7th December 2020 and used for all conversions from BDT to GBP

6.1.4.2 Burn characteristics

Burn characteristics are shown in Table 6-2. Flame burns were the most common cause of injury and were caused by cooking flames (16), gas combustion (6) kerosene lamps or candles (6), flash burns (4), floor fires (2), or children playing with fire (2). All scalds were caused by hot water at home or work. The four direct contact burns were to feet or ankles in childhood being burned by ash remnants from a floor fire. Two participants sustained their burns due to intentional assault (acid attack 1, bomb explosion 1).

Table 6-2: Burn characteristics

Burn Characteristics		Value
Cause of burn (n=48)	Flame Scald Chemical Contact	36 7 1 4
TBSA (n=27)	Median (IQ) Min-Max	25% (14%) 6-60%
TBSA Category (n= 48)	Minor (<15% TBSA) Moderate (15%-30% TBSA) Major (>30% TBSA)	16 21 11
Depth of Burn (n=20)	Superficial Full thickness Mixed depth	1 13 6

Documentation of TBSA was limited and data were only available for 27/48 participants (Table 6-2). If medical notes were available, TBSA was usually documented, 1 set of notes contained a TBSA chart documenting distribution and depth of burn. Some participants/relatives were able to report TBSA; this was accepted as TBSA data. In every case where TBSA was documented and also reported by the participant, the sources agreed. The two participants treated overseas had the largest TBSA burns (60% TBSA).

From limited medical notes and patient reports, it was only possible to determine the depth of burn in 20 of the participants. All but one of the participants used the English word 'deep' to report the depth of burn. Only

one superficial burn was reported by a participant (also documented as such in the medical notes), however, this participant had scarring in all areas of the burn injury which was not consistent with a superficial burn injury. Most burns that could be classified were full thickness injuries (13/20).

6.1.4.3 First aid

Participants were asked to describe the immediate action taken when the burn was sustained, which was recorded as first aid. Ten participants did not have any first aid, and 3 participants could not remember. The majority of those who did have first aid applied water only to the burn. Others applied a variety of remedies; medicinal ointment (n=3), toothpaste (n=2), ayurvedic or other natural remedy (for example egg or banana leaf, n=7). For the purposes of this study appropriate first aid was defined as application of water immediately after the burn, followed by immediate healthcare presentation. Of 35 participants who had first aid, 22 were deemed to have had appropriate first aid.

6.1.4.4 Inhalation injury

Eleven participants reported having an inhalation injury. A diagnosis of inhalation injury was only documented in the medical notes of 3 participants. Presence of inhalation injury was largely participant-reported after the translator explained the signs and symptoms of an inhalation injury. History of the injury was also considered in confirming the likelihood of inhalation injury. Nine of eleven participants who reported an inhalation injury had a stay in the Intensive Therapy Unit (ITU), which may support their claim. Only one participant was unsure whether they had an inhalation injury.

6.1.4.5 Co-morbidities

Only 4 participants reported any other health issues (epilepsy 3, asthma 1).

6.1.4.6 Infection

The state of the wound was not documented in any available medical notes. Infection was determined by patient report and any medical documentation of laboratory cultures where infective organisms were identified. Thirteen participants reported infection either because the doctor had informed them about it ($n=2$) or because they had to purchase antibiotics/creams ($n=5$). Many participants did not know if they had a wound infection ($n=15$).

6.1.4.7 Wound healing

Wound healing time was collected for each joint at risk where possible but was only available for 27 participants. Wound healing times were not documented in medical notes. A best estimate of time to heal was made through discussion between the researcher/interpreter and participant/carer. Full healing was defined as the burn area becoming healed/dry and when dressings were no longer required. Participants were only able to give approximations of the time to full healing in weeks and months. For those with more than one joint involved, the longest/last reported time to heal was selected to represent the time to heal at 'person' level. Wound healing times were long (median=16 weeks); the shortest healing time was 4 weeks and the longest 1 year.

Nutritional status is an important factor which contributes to wound healing; as a proxy for nutritional status, weight loss reported by the participant/family was documented. Weight (kgs) on in-patient admission was occasionally documented in medical notes, but weight on discharge was never documented. Data on nutritional status and several other variables, such as pain, were difficult to collect and unreliable.

6.1.4.8 Summary of burn factors

The majority of participants sustained their burn injury as adults. Time since injury varied. Flame burn was the commonest cause of injury. Two-thirds of burns were >15%TBSA. Limited data were available for burn depth, but in those for whom it could be determined, the majority of burns were full-thickness. Only a minority of participants had appropriate first aid, inhalation injuries, infection or co-morbidity, wound healing times were long. Data on pain and nutrition were difficult to extract and could not be analysed.

6.1.5 Health Care Access Data

6.1.5.1 No treatment

Participants were classified as receiving 'no treatment' if they had not received treatment for longer than 48 hours from any level of medical healthcare service. Five participants received all their initial burn care from a non-biomedical source (traditional healer, family friend or neighbour) and did not attend any formal healthcare provider. A further 2 participants attended a health facility initially but left within 24 and 48 hours respectively. All participants in the 'no treatment' group cited lack of funds as the reason why they did not seek definitive bio-medical care; in addition, 2 participants reported that they were not aware of the importance of appropriate burn care.

6.1.5.2 Type of care

Two participants were labourers in the Middle East at the time of burn and received their acute care in specialist burn centres in Oman and Dubai. Two participants had private burn care in specialist centres in Bangladesh, one at DMCH and one elsewhere in Dhaka. The remaining 37 participants (including the 7 participants in the 'no treatment' group) received their burn care in the Bangladesh Government health system.

6.1.5.3 First healthcare contact

All but 1 participant sought treatment (including non-biomedical care) within 24 hours of the injury; the remaining participant sought treatment one day after injury.

Participants presented to a wide array of formal and informal healthcare options as their first port of call. Upazila, District Hospital, Medical College Hospital and SHIBPS reflect ascending levels of burn care within the Government healthcare system, from primary to tertiary care. Of the 30 patients who received Government healthcare, 9 were treated initially at SHNIBPS. Both overseas workers returned to Dhaka on discharge from their acute overseas care and were outpatients at SHNIBPS. The most frequently accessed first healthcare contact was the District Hospital. Five participants sought care from traditional healers as their first care option.

Participants were asked what treatment they received at their first treatment stop; if the first healthcare stop was not a specialist burn service, care was very limited. Eight participants received no treatment at their first stop and were referred directly to a higher level of healthcare. Four received dressings only, 20 received basic burn care (IV fluid, dressings, pain relief and antibiotics) and one did not know what treatment he had received.

Burn care referral in Bangladesh is voluntary; participants may be advised to attend specialist care when accessing lower levels of healthcare, but travel to more appropriate facilities is voluntary and dependant on the participant's ability and will to attend.

Table 6-3 summarises the nature of healthcare treatment accesses for acute and definitive care.

Table 6-3: Healthcare access

Variable		Value
Healthcare treatment (n=48)	Yes	41
	No	7
First healthcare contact (n=48)	Family, friend, neighbour	3
	Traditional Healer	5
	Upazila health complex	8
	District Hospital	12
	Medical College Hospital	3
	Private institution	6
	SHNIBPS	9
	Overseas	2
Treatment stops prior to definitive care (n=44)	None	18
	One	18
	Two	8
Definitive care (n=48)	Family, friend, neighbour	6
	Traditional Healer	3
	Upazila health complex	4
	District Hospital	2
	Medical College Hospital	3
	Private institution	1
	SHNIBPS	27
	Overseas	2

6.1.5.4 Definitive care

For the purpose of this study, definitive care was defined as the final place of treatment or where most acute burn care was received. Nine participants received definitive care at home, 3 of whom had their definitive care provided by a traditional healer. For 18 participants, the first stop was also the definitive care location. Eighteen participants had one stop before arrival at definitive care and 8 had two stops before admission to definitive care.

Seven participants were classified as having 'no treatment' (i.e., spent <48 hours in any hospital); they are excluded from the evaluation of time (days) to definitive care. Only 4 of the remaining 41 participants reached definitive care more than 48 hours after injury. One of these reached definitive care after 74

days but went home after 7 days to collect funds before returning for definitive care >10 weeks later. One participant was treated as an outpatient for 30 days before being admitted for definitive care, another reached definitive care after 6 days (attempted treatment at home first) and the remaining participant reached definitive care after 10 days (sought care with a village doctor then a private institution before receiving definitive care in a District Hospital).

Only 11 participants received their initial care at a specialist burn care facility, including the 2 participants who received specialised care overseas (Oman and Dubai). Specialist burn care is available at other Medical College Hospitals across Bangladesh, however none of the participants treated within the Bangladeshi Government healthcare system received any burn specific, advanced or specialist care (such as ITU, skin grafting or any rehabilitative input) if not treated at SHNIBPS. The absence of specialist care outside of DMCH/SHNIBPS is further illustrated by the fact that participants in this study came from every region in the country and that all but one participant was advised by other centres to transfer to DMCH. The majority (27/48) of participants received definitive care at DMCH. Some participants were unable to follow the advice to transfer due to cost, lack of awareness or family demands, and either stayed at a lower level of healthcare or went home.

6.1.5.5 Discharge

Length of stay in hospital ranged from 1 week to 25 weeks (median 7.5 weeks, IQ 9.8). Data for 40 participants are presented; 7 participants did not have a hospital length of stay as they were treated at home and one participant could not remember how long they were in hospital. Length of stay was defined as time (weeks) admitted in healthcare facilities (Appendix 24).

Eleven participants of 42 patients admitted to hospital were discharged without medical consent. Two participants who were referred to a specialist

service from a lower level of healthcare but did not follow that advice were also included in 'discharged against medical advice'. The reasons given by participants for self-discharge against medical advice were lack of funds to continue treatment (n=5), fear of having surgery (n=2), responsibility for small children or other family members (n=3) lack of dignity and lack of trust in the nurses (n=1).

6.1.5.6 Follow up care

Healthcare follow-up in Bangladesh is patient-led; no appointments are given, and patients are advised to return in a given number of days, weeks or months. If they do not return, no further contact is made by healthcare providers.

In this study, follow-up was defined as any outpatient self-presentation within the first 3 months of discharge; 2 participants who attended for follow-up at 170 and 330 days respectively were excluded. Only 3 of the participants who had follow-up were seen at a healthcare facility other than DMCH (1 at Upazila level, 1 at Medical College level, 1 at a private facility).

Table 6-4 shows the wide range of time to first follow-up and the number of follow-up appointments.

Table 6-4: Follow Up

Variable	Value	
Follow up attendance (n= 48)	Yes	26
	No	22
Time to first follow up attendance (days) (n=26)	Median (IQ)	14.50 (23)
	Min - Max	7-84
Number of follow up attendances (n=26)	Median (IQ)	5 (8)
	Min - Max	1-120

Participants who did not attend follow-up were asked why they did not attend. The reasons were reported by one or more participants: not being told

to return (n=5), lack of finances (n=9), family resistance or responsibilities (n=12) and too fearful to return (n=2).

As follow-up was problematic for many participants, enquiry was made as to any self-care given at home, such as exercises. Ten participants attempted some kinds of exercises and 12 used a splint/massage/pressure garment at home. It was not possible to understand how appropriate or effective these were. In 2 cases, home treatment was initiated without professional advice; one mother made a bamboo arm splint for her son after she noticed his elbow had started to flex and another participant noticed development of a hip contracture and placed a brick on her knee whilst lying down to straighten the hip area.

6.1.5.7 Costs of care

Participants were asked to estimate how much their burn care had cost to date; most appeared to know the cost of care and were able to answer quickly. If the participant was accompanied by a relative, it was often the relative who would know the cost of care. Care costs were extremely high, especially in the context of reported monthly incomes (median cost = 300,000 BDT (or 3 Lakhs), IQ = 587,500, Min – Max = 10,000 – 20,000,000). Three Lakhs BDT is equivalent to £2,676.83; the average monthly income for the whole group was 19,273 BDT, or £170 per month. There were four outliers; 2 participants with the highest costs were treated overseas and had their acute care costs paid by their employers (20,000,000 BDT and 19,500,000 BDT, equivalent to £169,882 and £165,634 respectively), the 3rd highest cost was for private care (5,000,000 BDT, equivalent to £42,470) and the 4th outlier was the highest Government care cost (2,000,000 BDT, equivalent to £16,988). The remaining participants' care costs ranged from 15,000,000 BDT (equivalent £12,741) to 10,000 BDT (equivalent £85). Twelve participants did not know the cost of their care. Some participants

reported that the costliest part of their care was medication (n=16); others reported that the first few days/ITU was most expensive.

6.1.5.8 Summary of healthcare access

Most participants were treated in the Government system. Participants sought burn care promptly, usually within 24 hours of burn. Outside specialist burn centres, treatment was basic. Within the study population, specialist care was only received in Bangladesh at one private institution and DMCH/SHNIBPS. Length of stay in definitive care varied and 23% of participants were discharged against medical advice. Almost half of the participants had no follow-up at all, and for those who did, the frequency of follow-up was limited. Costs of care were high.

6.1.6 Treatment Factors

6.1.6.1 Escharotomy and fasciotomy

Three participants had an escharotomy or fasciotomy. Two participants' medical notes reported that an escharotomy had been carried out, confirmed by the participants/relatives. One further participant had no medical documentation of his report of an escharotomy, but it was observed that the area had been skin grafted; it was possible that an escharotomy had been performed. There were no escharotomy marks noted on any participant who did not report having had an escharotomy.

6.1.6.2 Amputation, neuropathy, heterotopic ossification

No participant had any amputation, neuropathy or heterotopic ossification, based on direct assessment by the researcher and available medical documentation.

6.1.6.3 ITU care

Most participants (35/48) did not have ITU care, which was only provided at DMCH or overseas. The median LOS in ITU for those who did have intensive care was 30 days (IQ = 31, Min, 4 Max, 90 days).

6.1.6.4 Skin grafting

Skin grafting was determined by medical notes, patient report and researcher observation. Twenty participants had at least one skin graft. All participants who had private care (2) or overseas care (2) had skin grafting. The remaining 16 grafted participants were treated at DMCH. Apart from 3 sheet grafts, all were meshed skin grafts. At ‘person’ level, participants were classified as having a skin graft if they had any skin graft at any included joint. Table 6-5 presents the data pertaining to skin grafting. The success rate of grafts was high (85%) with only 3 graft failures. Six participants refused skin grafts; reasons given were fear of surgery/death (n=2), lack of funds (n=3), need to care for a small baby at home (n=3) and lack of dignity given by the nurses in the hospital (n=1).

Table 6-5: Skin grafting

Variable	Value	
Skin grafted (n=48)	Yes	20
	No	28
Time to first graft (n=20)	Median (IQ)	4 (4.8)
	Min-Max	1.5-24
Number of grafts per person (n=20)	Median (IQ)	1 (1)
	Min-Max	1-4

6.1.6.5 Rehabilitation

Only participants who received private, overseas, or DMCH/SHNIBPS care received physiotherapy. Occupational therapy was not offered to any participant. There was no documented professional physiotherapy or

rehabilitation treatment in medical notes, other than doctors' orders for splints, pressure garments and/or physiotherapy for some participants.

Physiotherapy input was defined as at least one visit/consult with a qualified physiotherapist; physiotherapy input is described in Table 6-6. The first encounter with physiotherapy was very late post-injury and the time spent with the participant was short. Of those seen by a physiotherapist, 6/19 (32%) were seen only once.

Table 6-6: Physiotherapy input

Variable	Value	
Seen by a physiotherapist (n=19)	Yes	19
	No	29
Type of physiotherapy (n=19)	No input	29
	Inpatient	3
	Outpatient	7
	Both	9
Time to first physiotherapy from date of injury (days) (n=19)	Median (IQ)	48.50 (95)
	Min-Max	2-195
Length of physiotherapy session (minutes) (n=19)	Median (IQ)	10 (14)
	Min-Max	0-60
Number of times seen by a physiotherapist (n=19)	Once	6
	2 – 7 times	4
	8 – 20 times	2
	> 20 times	6

Physiotherapy treatments were more often advised by doctors rather than delivered by physiotherapists; doctors made referrals for splints and pressure garments, which were generally provided by an orthotist rather than a physiotherapist. Therefore, it was common for a participant to have had a therapy-related treatment without direct input from a physiotherapist.

The rehabilitation treatments received by participants were splints (14/48, 29%), exercise advice (27/48, 56%), positioning (19/48, 40%), scar massage (22/48, 46%) and pressure garments (17/48, 35%).

Various pressure garments and splints were provided; these included 5 chin straps (chin and neck), 11 vests, 4 sleeves, 1 gauntlet (wrist), 2 leggings, 9 neck soft collars, 2 aeroplane splints (shoulder), 2 elbow splints (one made from bamboo and one ready-made) and 1 knee splint (plaster of Paris). Apart from the participant who had a bamboo elbow splint, all participants who had a pressure garment or a splint were treated at DMCH, either as an inpatient or an outpatient.

6.1.6.6 Psychosocial rehabilitation

Only one participant had seen a professional counsellor at any time. This was a patient treated initially in Oman, who was seen there by a psychiatrist for post-burn 'delirium'. No psychosocial support was given in Bangladesh.

6.1.6.7 Summary of treatment factors

The majority of participants did not have any escharotomy or intensive care. Less than half the participants had any skin graft; some who were offered a skin graft refused it. A minority of participants were seen by a physiotherapist, but not for long, mostly infrequently and usually late after injury. ITU, skin grafts and physiotherapy were only available in specialist centres. Rehabilitation treatments were advised by both doctors and physiotherapists. The focus of these interventions was on advice rather than hands-on treatment with a physiotherapist. Most participants did not have any therapy interventions apart from exercise advice. Post-burn counselling was not offered in Bangladesh.

6.1.7 Participant Awareness and Opinion

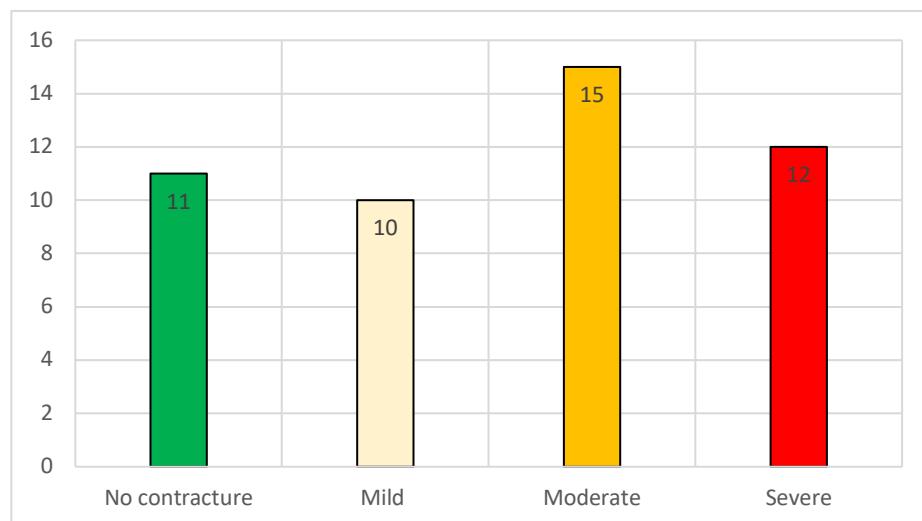
Participants were asked if they had heard the word 'contracture', and if so, in what setting and from whom had they heard it. Only 12 participants had heard the word 'contracture', in all cases at the time of their acute burn injury.

Participants were also asked if they had been aware that contracture could develop following a burn. At the time of acute care, 28/48 participants did not know that they could develop a contracture. Further questions were asked of participants to gain better understanding of their perceptions of contracture, such as the time when the contracture began to develop, why they believed it was difficult to move the joint at risk, whether the contracture got worse or better over time and at what point the contracture became fixed in its current position. Most participants were uncertain in their responses to these questions and were very unclear on time points. An attempt was made to collect the data, but it was deemed to be too sparse and unreliable to report or use in analyses.

6.1.8 Contracture Outcomes at Person Level

This section reports the distribution of whole person outcomes (BCSCp and LMSp), which were used in the following chapter to analyse risk factors. Figure 6-2 shows the distribution of participants according to the severity of their worst contracture (BCSCp). There were similar numbers of participants in each worst contracture severity group; the category with the most participants was moderate ($n=15$).

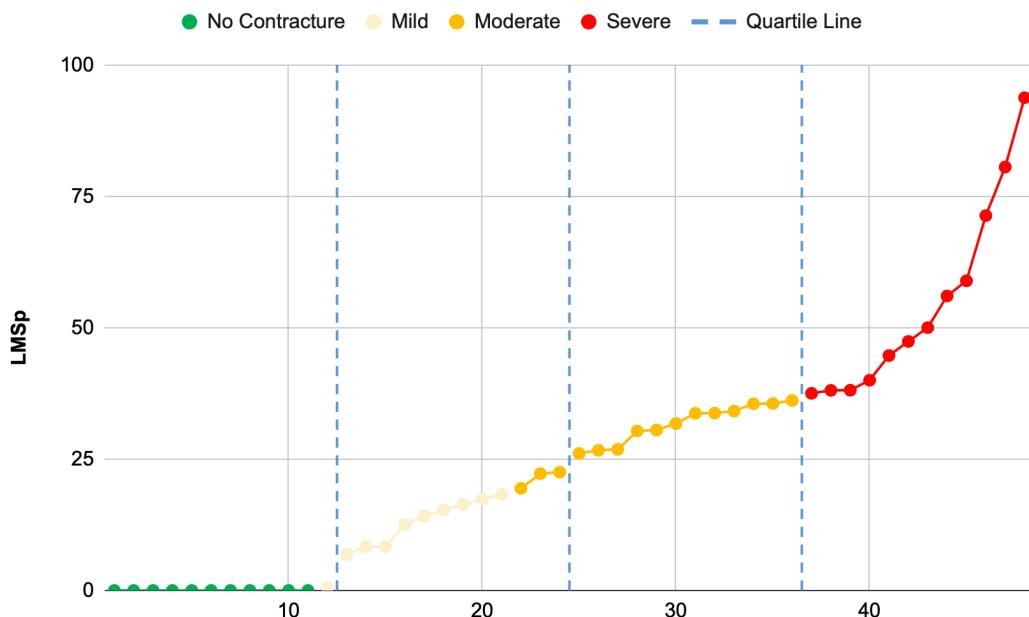
Figure 6-2: Number of participants by BCSCp category



LMSp represents the mean proportion of movement lost across all joints at risk per participant. The median LMSp for the study population was 24.29% (IQ = 35.10, Min = 0 – Max 93.75).

The relationship between BCSCp and LMSp is displayed in Figure 6-3, which plots each participant's LMSp, colour-coded according to their BCSCp category. LMSp quartiles are indicated by dotted lines.

Figure 6-3: The four quartiles of LMSp and fit with BCSCp



The first quartile of LMSp includes all the BCSCp 'no-contracture' participants; one additional participant with minimal LMSp loss (5%) and a mild contracture by BCSCp also fell in this quartile. The second LMSp quartile captured all mild contractures as defined by BCSCp and 3 participants with moderate contractures. The 3rd LMSp quartile contained all remaining moderate contractures. The 4th LMSp quartile included all the BCSCp severe contractures.

Figure 6-3 suggests a close relationship between BCSCp and LMSp, which is interesting as BCSCp is based on the participants' worst contracture while

LMSp takes account of the loss of movement at all joints at risk. Previous to this study, neither BCSCp or LMSp have been used to indicate contracture severity at the person level.

6.2 OVERVIEW OF JOINTS AT RISK

6.2.1 Location of joints at risk

The 48 participants had a total of 126 joints at risk of contracture (mean joints at risk/person = 2.6, (median 3, range 1-6). Most joints at risk (107/126) were in the upper body (neck, shoulders, elbows, wrists). Lower limb joints (hip, knee, ankle) accounted for 19/126 joints at risk.

The numbers described for each joint location are combined for the right and left sides of the body. The wrist was the most frequently observed joint at risk (n=33) and the hip was least frequently at risk (n=2). The knee was the most common lower limb joint at risk (n=11).

6.2.2 Joint treatment interventions

Some risk factors, although also considered at person level, were more pertinent at joint level. Over 60% (76/126) of all joints at risk were not grafted. In the 50 grafted joints, average time from injury to first graft was 7 weeks (SD 8.33, range 1-5-52 weeks). The mean time for wounds over joints to heal was 19 weeks (SD 14.34, range 4-104 weeks). Infection was reported (by participants or laboratory culture) in 38 (40%) of the 94 joints for whom data were available.

Most joints did not receive any of the main physiotherapy interventions (Table 6-7). The most frequently used intervention was pressure (applied in 37% joints). Only 22% of joints were positioned and only 17% were splinted.

Initiation of interventions was late by HIC standards and the duration of all the interventions was short. Intervention effectiveness could not be determined for most joints; the limited data available suggests that pressure was effective in 75% joints, splints in 43% and positioning in only 14%. Overall, only a third of all therapy interventions were deemed effective.

Table 6-7: Therapy Interventions at joint level

Variable		Value
Splinted (n=126)	Yes No	21 105
Time to first splint (weeks) (n=20)	Mean (SD) Median (IQ) Min-Max	7.93 6 (10.6) 0.5-24
Effective Splinting (n=21)	Yes No	9 12
Pressure (n=126)	Yes No	46 80
Time to first pressure (weeks) (n=46)	Mean (SD) Median (IQ) Min-Max	15.65 14 (8) 6-40
Effective Pressure (n=46)	Yes No	17 29
Positioning (n=115)	Yes No	28 87
Time to first position (weeks) (n=11)	Mean (SD) Median (IQ) Min-Max	18.85 0.50 (10) 0-97
Effective Positioning (n=28)	Yes No	4 24

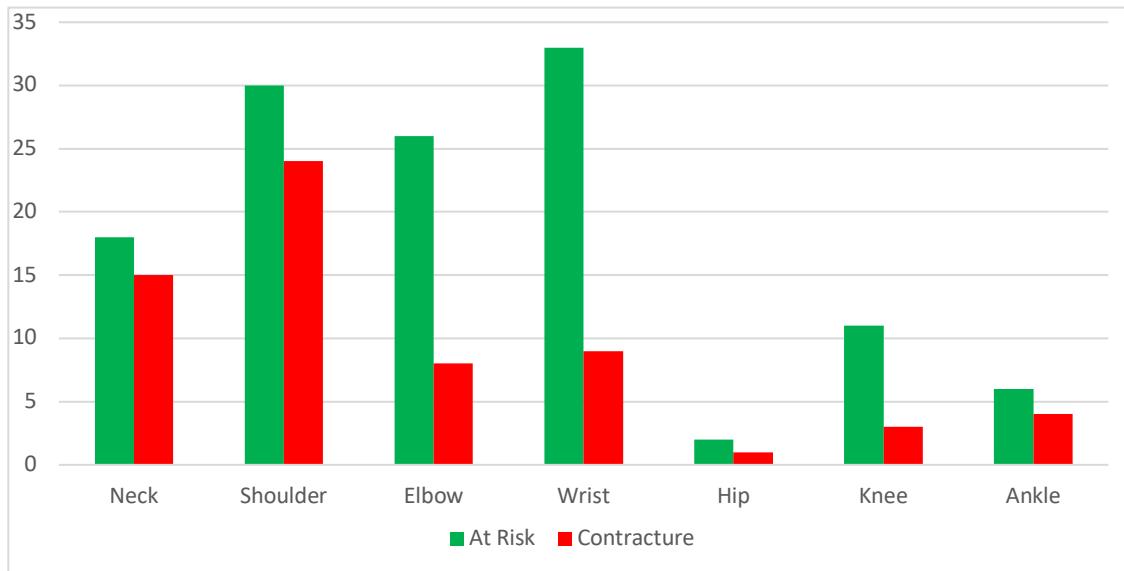
6.2.3 Contracture outcomes at joint level

6.2.3.1 Presence of contracture

Overall, 37/48 (77%) participants had contractures of at least one major joint at risk. The distribution of joints at risk and contractures is shown in Figure 6-4. Although the number of joints at risk was considerably higher in the upper body than lower body, there was less disparity between the overall contracture

rates of the upper and lower body. In the upper body, 56/107 joints at risk (52%) developed a contracture, compared with 8/19 (42%) of lower limb joints at risk.

Figure 6-4: Joints at risk and contracted by anatomical location



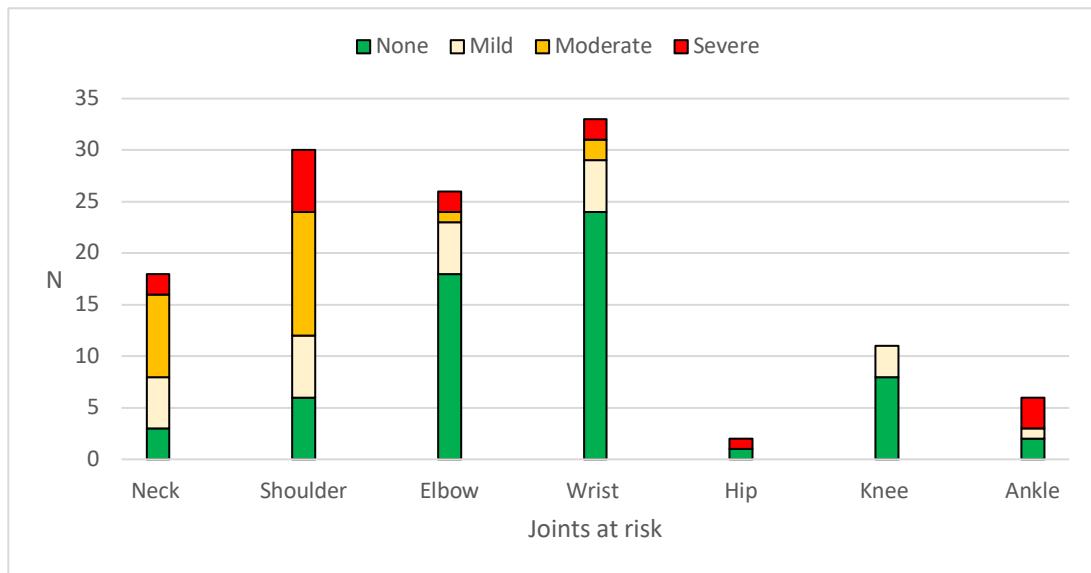
The shoulder and neck had considerably higher contracture rates than the elbow and wrist. Only 6/30 shoulders and 3/18 necks did not develop a contracture.

In the lower body, the ankle had the highest contracture rate; 4/6 ankles developed a contracture. Only two hips were at risk; one became contracted, and one did not. Only 3/11 knees that were at risk developed a contracture, giving a contracture rate of 27%; together with the wrist, this was the lowest contracture rate observed.

6.2.3.2 Contracture severity

Joint contracture severity was described as mild, moderate, or severe by BCSCj. Actual loss of movement at each joint was described by LMSj. The BCSCj severity classifications of joints at risk are shown in Figure 6-5.

Figure 6-5: BCSCj by Joint Location



Eighteen (60%) shoulders had moderate or severe contractures. In contrast, 88% of wrists (29/33) and elbows (23/26) had either no or only mild contractures.

In the lower limb, ankles developed the most severe contractures. In contrast, the majority of knees did not develop any contracture (8/11, 73%). The one contracted hip developed a severe contracture.

Table 6-8 reports the proportion of movement lost (LMSj) at each joint for all joints at risk and for contracted joints only. When including joints with no contracture, the wrist was one of the joints with least movement loss, but when only contracted joints were analysed, the wrist had the third highest loss of movement. This suggests that while an 'at risk' wrist is less likely to become contracted than other joints, when it does, the severity of contracture is greater. With the exception of the wrist, there was no difference in the ranking of movement loss for other joints when only contracted joints were analysed.

Table 6-8: LMS_j at each joint location

Joint		Mean LMS _j (%) (SD)	Median LMS _j (%) (IQ)	Min-Max (%)
Neck	All (18)	36 (24)	33 (39)	0-73
	Contracted (15)	42 (33)	33 (36)	20-73
Shoulder	All (30)	35 (27)	33 (38)	0-89
	Contracted (24)	44 (23)	39 (30)	7-89
Elbow	All (26)	12 (23)	0 (12)	0-76
	Contracted (8)	34 (23)	39 (30)	7-76
Wrist	All (33)	11 (26)	0 (10)	0-100
	Contracted (9)	47 (37)	33 (37)	3-100
Hip	All (2)	50 (71)	50 (50)	0-100
	Contracted (1)	100	100	100
Knee	All (11)	9 (12)	0 (14)	0-40
	Contracted (3)	24 (14)	17 (0)	14-40
Ankle	All (6)	50 (50)	50 (1)	0-100
	Contracted (4)	75 (42)	94 (68)	13-100

At the hip, wrist and ankles, some joints had 100% loss of movement. The knee had the smallest range of movement loss, and the wrist the largest range of movement loss (Figure 6-6).

Figure 6-6: Contracted joints by LMS_j and joint location

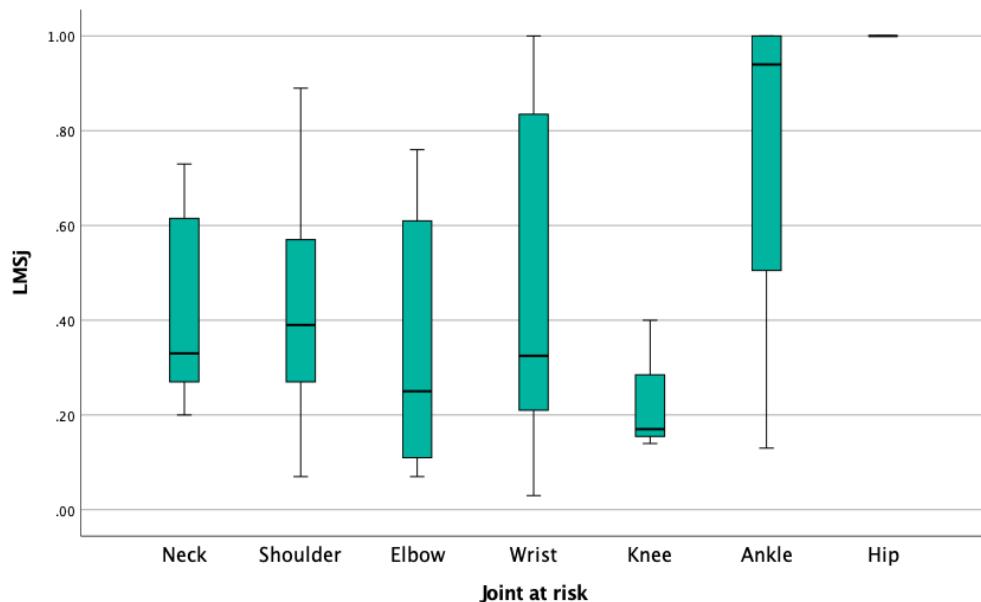
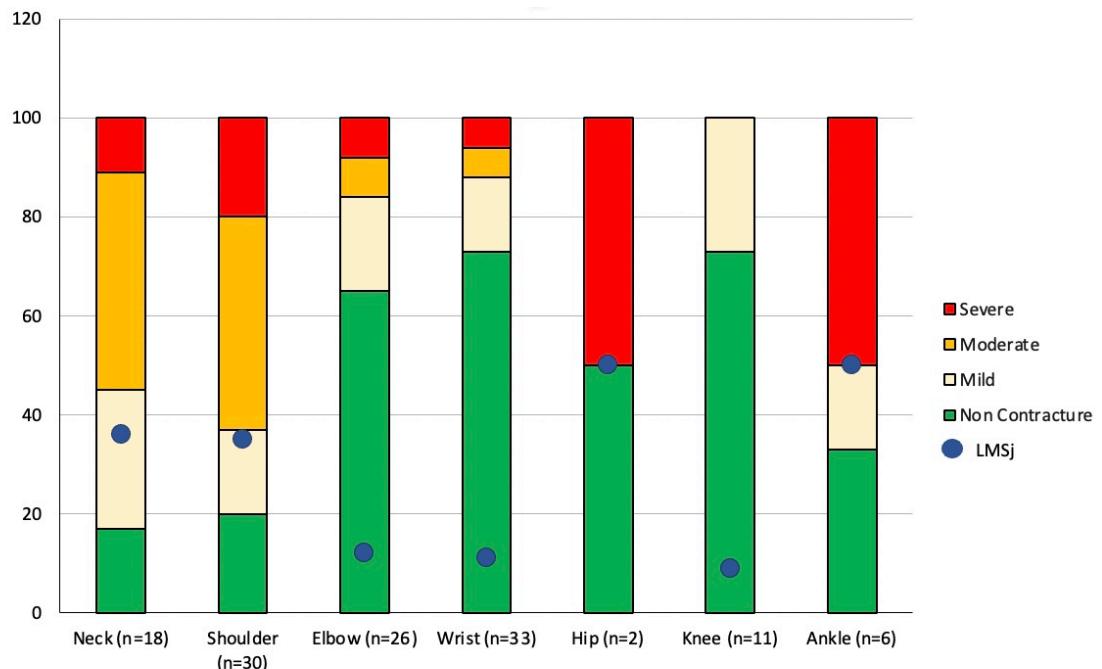


Figure 6-7 superimposes the two severity outcomes; the coloured stacks represent BCSCj categories, and the blue dots represent mean LMSj for each joint location.

Figure 6-7: BCSCj and LMSj



The elbow, wrist and knee had higher proportions of joints which did not contract, as reflected by both BCSCj and LMSj. The ankle had the highest proportion of severe contractures for any joint by BCSCj and demonstrated the highest LMSj. The neck and shoulder had the highest proportion of movement loss determined by LMSj and the greatest proportion of severe or moderate contractures by BCSCj. The elbow and knee consistently demonstrated least severe losses of movement. The knee had no severe contractures determined by BCSC; elbow and knee joints were most frequently classified as having no contracture. Consistent with this, the elbow and knee had least loss of movement according to the LMSj.

6.3 SUMMARY: STUDY POPULATION DESCRIBED

Study participants (n=48) were in general young, poor and unemployed. They travelled long distances to attend DMCH/SHNIBPS and came from all over Bangladesh. Their injuries were caused mostly by flame burns during adult life. TBSA and burn depth were hard to determine for all participants but most burns were >15%TBSA and full thickness. Co-morbidities were rare.

Participants had received a diverse range of first aid and initial care, but most were treated within the Government health system. Nearly all participants presented within a timely manner to healthcare. The minority of participants received specialist burn care throughout. Participants had received few surgical or therapy interventions. Interventions provided were initiated late and for short durations and were available only in specialist healthcare services.

Participants had a median of 3 major joints at risk. Most participants had contractures of at least one joint at risk at person level. At person level, the participants' worst contracture was most frequently moderate (31%), with a median LSMP of 24% for the whole group. At joint level, 51% of joints at risk were contracted. The contracture rate was higher in some joint locations (neck and shoulder) than others (elbows, knees, and wrists). Neck, shoulder, and ankle joints were more severely contracted than other joint locations.

7 RESULTS II: RISK FACTORS FOR CONTRACTURE DEVELOPMENT

This chapter presents the results of analyses of risk factors by contracture presence and severity at both whole person and joint levels. As described previously, whole person outcomes were defined as presence/absence of contracture, person contracture severity (BCSCp) and mean proportional loss of movement over all joints at risk (LMSp). Individual joint outcomes were defined as contracted/not contracted, severity of joint contracture (BCSCj) and proportional loss of movement (LMSj) for each included joint.

7.1 WHOLE PERSON RISK FACTORS AND OUTCOMES

All risk factors were examined for any relationship to contracture presence/absence in all 48 participants. Despite having at least one study joint at risk, only 8% of participants did not have any contracture(s) of any feature or joint. The only risk factor for which there was a statistically significant difference between participants with (n=37) and without contractures (n=11) was the depth of the burn (Chi Square = 8.24, df = 2, p = 0.02).

Results are grouped by category of risk factor examined i.e., demographic, socio-economic, burn injury, healthcare access, treatment and participant awareness and opinion.

7.1.1 Demographic Risk Factors

A summary of demographic risk factors and outcomes are shown in Table 7-1. Contracture severity was evenly distributed between males and females except for mild contractures; four times as many males than females had mild contractures. Females were most frequently categorised to have moderate contractures by BCSCp. LMSp showed a median loss of movement twice as

high (34.13% loss) in women compared to men (median = 17.33% loss) but these differences between male and females was not statistically significant.

Contracture outcome was statistically significantly affected by age, both at the time of burn injury and age at interview. Participants with mild contractures at the time of interview were older than those in other severity categories; this difference was statistically significant (Kruskal Wallis = 9.89, df=3, p = 0.02), Figure 7-1. LMSP did not show any statistically significant relationship between current age and loss of movement (Table 7-1).

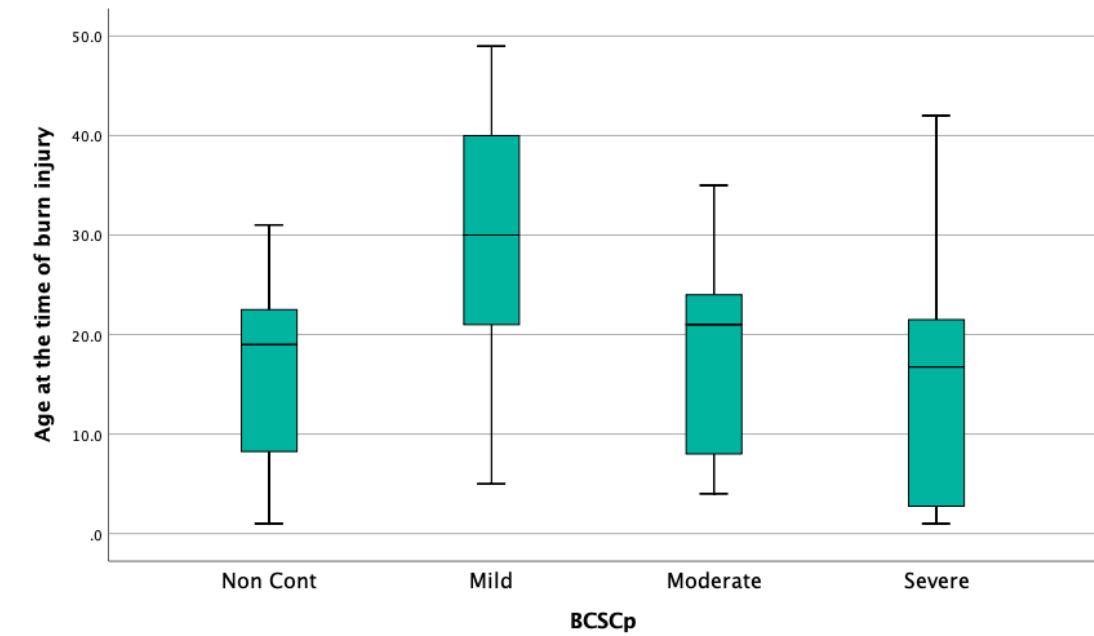
Participants with mild contractures, who also had the shortest interval since their burns, were statistically significantly older at the time of burn, than those in any other contracture severity group (Kruskal Wallis=10.70, df=3, p=0.01). There was no statistically significant relationship between age at the time of burn and LMSP (Table 7-1).

Almost half of those burned <5 years of age had severe contractures, but there was no statistically significant difference in contracture severity between age groups (< 5 years old, 5-17 years old and 18+ years). LMSP was greatest in those burned between 5–17 years of age (median 33.70, IQ 30.14) and least in those who were adults (median 20.82, IQ 31.97) at the time of injury, but these differences were not statistically significant.

Table 7-1: Demographic risk factors

Risk Factor		Severity Classification - BCSC					LMSP		
		None	Mild	Mod	Severe	p	Median (IQ)	Min-Max	p
Gender (n=48)	Male (n=25)	5	8	7	5	0.28	17.33 (29.08)	0 - 93.75	0.13
	Female (n=23)	6	2	8	7		34.13 (40)	0 - 71.32	
Age at interview (n=48)	Median IQ Min - Max	25 (9.8) 18 - 33	32.50 (16.3) 22 - 53	23.50 (7.8) 18 - 35	22 (11) 18 - 42	0.02*			0.11
Age at burn (Years) (n=48)	Median IQ Min - Max	18 (20) 1 - 31	30 (20) 5 - 49	22 (16.5) 4 - 35	16.5 (18.5) 1 - 42	0.01**			0.11
Years since burn (n=48)	Median IQ Min - Max	5 (15.50) 0.75- 26.50	2.5 (3.13) 0.75- 21	1.5 (9.25) 0.11- 16	4.25 (17.44) 0.50- 337.50	0.57			0.71
Home Location (n=48)	In Dhaka (n=19)	5	5	7	2	0.33	26.67 (36.15)	0 - 56.02	0.57
	Outside Dhaka (n=29)	6	5	8	10		22.50 (31.31)	0 - 93.75	
Home Type (n=48)	Rural (n=27)	5	6	7	9	0.72	26.85 (29.76)	0 - 93.75	0.41
	Semi-urban (n=10)	3	1	4	2		18.76 (30.84)	0 - 35.56	
	Urban (n=11)	3	3	4	1		26.67 (40)	0 - 80.56	
Km from home to hospital (n=45)	Median IQ Min- Max	95 (238) 2 - 400	82.50 (187) 1 - 300	75 (163) 10 - 400	180 (230) 35 - 350	0.47			0.30
Hours from home to hospital (n=48)	Median IQ Min - Max	2.5 (4) 1 - 9	3 (2.6) 1 - 8	4.50 (4.5) 1 - 12	4.50 (3.6) 1 - 11	0.41			0.18

Figure 7-1: BCSC and age at the time of burn injury



The time since injury was not statistically significantly related to outcome by either BCSCp or LMSp (Table 7-1). The longest intervals from injury were in participants with no contractures (median 5 years) and those with severe contractures (median 4.25 years), Table 7-1.

With respect to residence location, participants were analysed in two groups, those living in Dhaka division and those living outside. Dhaka division ($20,509 \text{ km}^2$) extends beyond Dhaka city and includes rural areas. Only 2/19 participants living inside Dhaka division had a severe contracture, compared with 10/29 participants from outside Dhaka. There was no significant difference in median LMSp between the two groups (Table 7-1).

Only 1/11 participants who lived in urban areas had a severe contracture, compared to 9/27 participants who lived in rural areas. Those from semi-urban areas had the lowest LMSp (median 18.76%) compared to other groups. There were no significant differences in BCSCp or LMSp by residence location.

Although there was no statistically significant difference among the groups, participants with severe contractures lived considerably further from DMCH than other groups, Table 7-1. Participants with severe contractures lived a median of 180 kms from SHNIBPS/DMCH (range 35-350km). In contrast, those without contractures lived at a median of 95km from SHNIBPS/DMCH.

The length of time taken to reach DMCH from home progressed with increasing contracture severity; those with no contractures had a median of 2.5 hours travel time, while those with minor contractures travelled for a median of 3 hours and those with moderate/severe contractures for a median of 4.5 hours. This difference was not statistically significant. There was also no statistically significant relationship between travel time to SHNIBPS/DMCH and LMSp, Table 7-1.

7.1.1.1 Summary of demographic risk factors

The only statistically significant demographic risk factors were age at time of burn injury and interview; at both time points participants who were older had more mild contractures than any other severity classification. Although not statistically significant, severe contractures were more common in women and in participants who lived further (in kms and time) from DMCH. Participants who lived in rural areas had more severe contractures by BCSCp, however movement loss (LMSp) was similar for all residence locations.

7.1.2 Socio-Economic Risk Factors

For risk factor analyses, participants were initially analysed in 2 categories (employed vs unemployed), then by employment status (unemployed/manual /non-manual). Employed participants had statistically significantly fewer contractures than those who were unemployed. Contracture severity was also statistically significantly greater in unemployed participants by BCSCp (Chi

Chi Square = 8.33, df = 3, p = 0.04) and by LMSp (Mann Whitney = 159.5, p=0.01) (Table 7-2).

Nineteen of 26 (73%) unemployed participants had moderate or severe contractures. For those in non-manual work, contractures were either absent or only mild. These differences were statistically significant (Chi Square = 13.45, df = 6, p = 0.03). LMSp also showed a statistically significant difference in movement lost between the 3 employment groups (Table 7-2, Figure 7-2). Unemployed participants had the greatest loss of movement and the non-manual group the least loss (Kruskal Wallis 7.89, df 2, p=0.02).

There was no statistically significant difference in outcome between participants who were literate and those who were not, although unexpectedly, LMSp appeared greater in the literate group than in the illiterate group (Table 7-2).

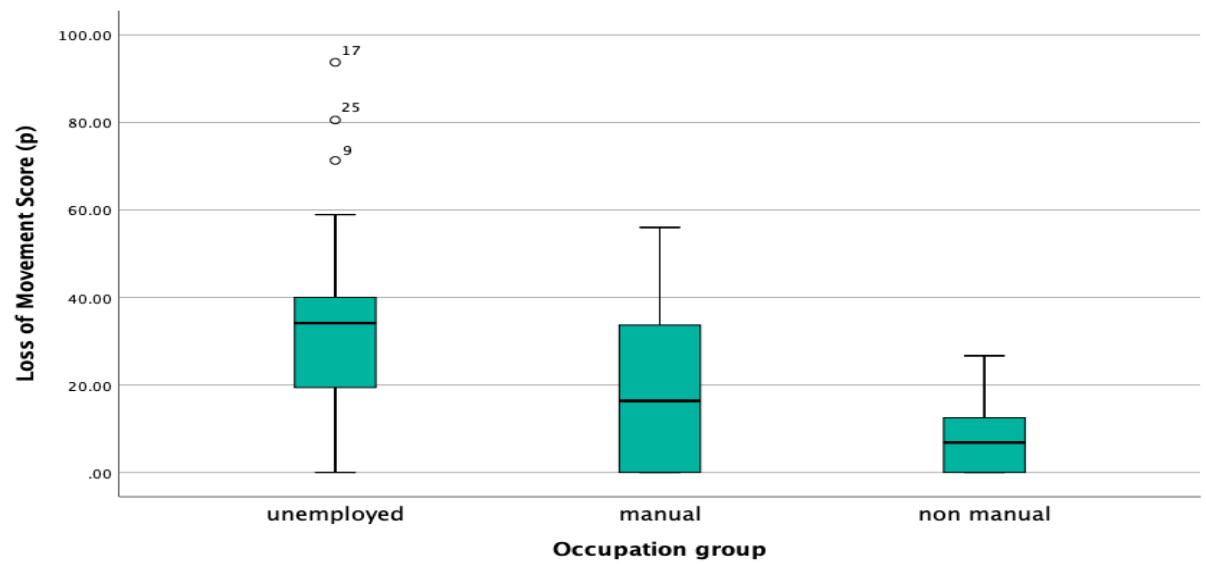
There were no statistically significant differences in outcomes for different levels of education (Table 7-2). LMSp showed that those who had, or were in, tertiary level education had the greatest loss of movement across all joints at risk which was unexpected. Those who had secondary level education demonstrated the lowest LMSp.

Table 7-2: Socio-economic risk factors

Risk Factor	Severity Classification - BCSC					LMSp		
	None	Mild	Mod	Severe	p	Median (IQ)	Min-Max	p
Employment (n=48)								
Unemployed (n=26)	3	4	9	10	0.04*	32.33 (24.99)	0 – 93.75	0.01**
Employed (n=22)	8	6	6	2		13.33 (32.25)	0 – 56.02	
Employment type (n=48)								
Unemployed (n=26)	3	4	9	10	0.03*	34.13 (24.99)	0 – 93.75	0.02*
Manual (n=17)	6	3	6	2		16.36 (33.72)	0 – 56.02	
Non manual (n=5)	2	3	0	0		6.85 (19.58)	0 – 26.67	
Literacy (n=48)								
Illiterate (n=10)	2	2	3	3	1.00	18.33 (31.39)	0 – 38.10	0.59
Literate (n=38)	9	8	12	9		26.37 (37.84)	0 – 93.75	
Education (n=47)								
None (n=6)	1	3	0	2	0.68	22.60 (31.40)	0 – 38.10	0.61
Primary (n=12)	2	2	5	3		28.12 (35.74)	0 – 71.32	
Secondary (n=18)	6	3	6	3		16.86 (34.16)	0 – 93.75	
Tertiary (n=11)	2	2	4	3		30.32 (29.30)	0 – 80.56	
Household Income (£/month) (n=42)								
Median IQ	£93 (£153)	£127 (£62)	£127 (£117)	£85 (£85)	0.50			
Min - Max	£13 - £1,019	£85- £595	£8.50 - £255	£42 – £425				

Despite the range of monthly incomes, no statistically significant differences in outcomes (assessed either by BCSC or LMSp) were found in relation to household income (Table 7-2).

Figure 7-2: Occupation and LMSp



7.1.2.1 Summary of socio-economic risk factor analyses

Contracture outcomes determined by both BCSCp and LMSp were statistically significantly affected by employment status and type. Those who were unemployed had most severe contractures and greatest movement loss. Those who had non-manual jobs had least severe contractures and movement loss.

No other socio-economic risk factors showed any statistically significant effects. There was little variation in outcome related to education level or household income, which was unexpected. Literate participants and those in tertiary education had greater movement loss than those who were illiterate and had studied to lower levels of education, which was also surprising.

7.1.3 Burn Injury Risk Factors

There were no statistically significant differences between the different causes of burns and contracture outcomes by either BCSC or LMSp, Table 7-3.

Table 7-3: Burn injury risk factors

Risk Factor		BCSC Classification				p	LMSp		p
		No	Mild	Mod	Severe		Median (IQ*)	Min-Max	
Cause of burn (n=48)	Flame (n=36)	9	6	14	7	0.42	24.28 (34.28)	0- 80.56	0.79
	Scald (n=7)	1	3	1	2		22.22 (46.92)	0- 71.32	
	Chemical (n=1)	0	0	0	1				
	Ash (n=4)	1	1	0	2		31.25 (79.69)	0- 93.75	
TBSA Category (n=48)	0-15% (n=16)	3	3	4	6	0.61	34.63 (35.88)	0- 71.32	0.13
	15 – 30% (n=21)	6	3	7	5		19.42 (0- 36.82)	0- 93.75	
	30% + (n=11)	2	4	4	1		15.29 (26.20)	0- 33.73	
TBSA % (n=27)	Median IQ Min - Max	25 (29) 15 - 60	31.50 (22) 20 - 45	25 (12) 6 - 60	16.50 (29) 8 - 45	0.78			0.22
Depth of Burn (n=20)	Superficial (n=1)	0	1	0	0	0.02*			0.06
	Mixed (n=6)	3	0	2	1		7.08 (28.08)	0- 34.13	
	Full thickness (n=13)	0	2	7	4		31.76 (24.03)	8.33- 80.56	
Appropriate First Aid (n=35)	Yes (n=22)	4	4	9	5	0.93	30.28 (22.13)	0- 80.56	0.86
	No (n=13)	2	3	4	4		30.32 (22.13)	0- 71.32	

7.1.3.1 TBSA

Unexpectedly, contracture severity (BCSCp) appeared to reduce as TBSA% category increased. Analysis of LMSp by TBSA category also demonstrated that the greatest movement loss was in the lowest TBSA group (0-15%TBSA). However, these differences were not statistically significant. In the 27 participants for whom actual TBSA burned was available, findings were similar. Participants with mild contractures had the highest TBSA and those with severe contractures had the lowest TBSA, but these differences were not statistically significant (Table 7-3).

7.1.3.2 Depth of burn

Only 1 burn was superficial; this participant developed a mild contracture. All participants with full thickness burns developed contractures and 3/6 participants with mixed depth burns developed contractures. The difference in outcomes across the three different burn depths were statistically significant (Chi Square = 14.17, df = 6, p = 0.02); significantly more than expected full thickness burns developed a contracture (Standardised Residual = 2.2).

It was not possible to report a median LMSp for superficial burns as there was only one participant in this group, whose LMSp was 18.33%. LMSp also showed a greater loss of movement in participants with full thickness burns compared to those with mixed depth burns but unlike BCSCp, the difference was not statistically significant (Table 7-3).

7.1.3.3 First Aid

The data presented for first aid in Table 7-3 represent the participants who had appropriate first aid. There was no statistically significant difference in contracture outcome by BCSCp or LMSp between those who had appropriate first aid and those who did not.

7.1.3.4 Inhalation injury

Eight of 11 participants with inhalational injury developed moderate or severe contractures. However, half of those without inhalation injury (18/36) also had moderate or severe contractures. Participants without inhalation injury were equally represented in every contracture severity group. LMSp indicated similar losses of movement for those with inhalation injury (median loss 26.06%) and those without (median loss 22.36%) (Table 7-4). Inhalation injury was not significantly related to outcome.

Table 7-4: Burn injury risk factors: Medical factors

Risk Factor		Severity Classification - BCSC				p	LMSp		p
		No	Mild	Mod	Severe		Median (IQ*)	Min-Max	
Inhalation Injury (n=47)	Yes (11)	2	1	5	3	0.53	26.06 (36.36)	0- 80.56	0.70
	No (36)	9	9	9	9		22.36 (35.88)	0- 93.75	
Co-morbidities (n=48)	Yes (5)	0	2	1	2	0.37	22.22 (37.50)	0- 93.75	0.26
	No (43)	11	8	14	10		26.85 (36.15)	0- 80.56	
Infection (n=33)	Yes (n=13)	3	3	6	1	0.83	19.42 (27.97)	0-50	0.60
	No (n=20)	4	5	7	4		23.01 (35.39)	0- 80.56	
Wound healing (weeks) (n=42)	Median IQ Min-Max	12 4-52	12 7-52	20 0-52	12 0-104	0.64			0.87

7.1.3.5 Wound healing

Healing times were longest in participants with moderate contractures (median 20 weeks) compared with 12 weeks in other BCSCp groups, but this was not statistically significant. There was no statistically significant relationship between healing time and LMSp (Table 7-4).

7.1.3.6 Comorbidities

Only 4 participants had comorbidities, which is too few for meaningful analysis. All 4 participants who had co-morbidities developed a contracture, but the presence of comorbidities did not statistically significantly affect outcomes.

7.1.3.7 Infection

The presence of infection was difficult to ascertain. No differences in contracture outcomes were observed between participants with or without infection (Table 7-4).

7.1.3.8 Summary of burn injury risk factors

TBSA burned was highest in participants without contractures and lowest in participants with severe contractures, which was surprising but not statistically significant. Full thickness burns were statistically significantly associated with more severe BCSCp category but not with higher LMSp. No other burn injury factors were statistically significantly related to contracture outcome.

7.1.4 Healthcare Access Risk Factors

7.1.4.1 Treatment vs no treatment

There were no differences in BCSCp outcomes between participants who had no treatment compared with those who had treatment. Using LMSp, participants who had no treatment had greater loss of movement (median loss 30.32%) than those who had treatment (median loss 22.50%), but the difference was less than expected. There was no statistically significant difference between those who had not had any medical care and those who had, with respect to contracture severity (Table 7-5).

7.1.4.2 Sector of care

Sector of care was analysed by 3 groups - those receiving Government, private or overseas care. Participants having overseas or private care had less movement loss compared to those receiving Government healthcare. However, type of care did not statistically significantly affect BCSCp or LMSp outcomes (Table 7-5).

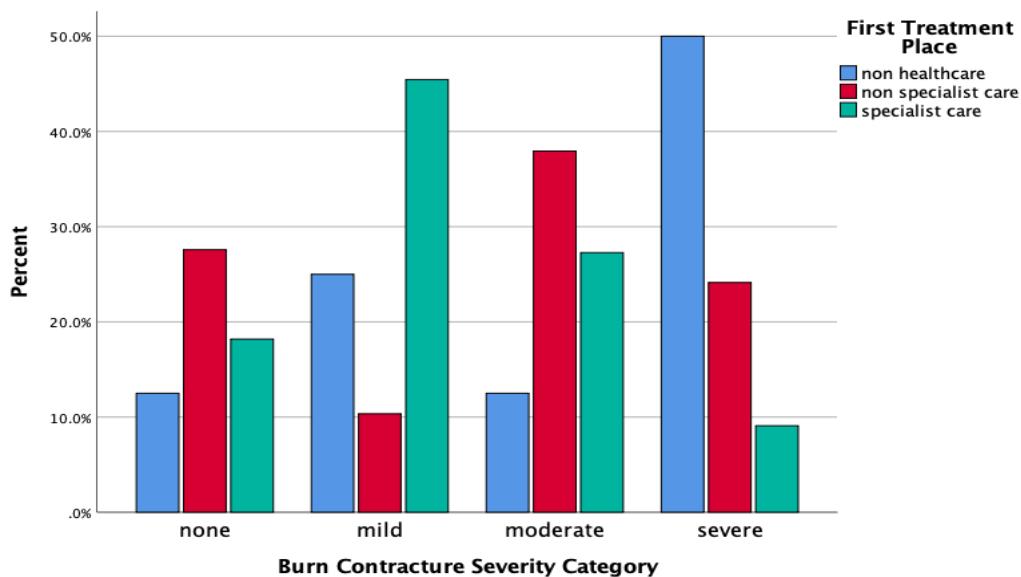
Table 7-5: Health care access risk factors

Risk Factor		Severity Classification - BCSC					LMSp		
		None	Mild	Mod	Sev	P	Median (IQ)	Min-Max	P
Treatment (n = 48)	Yes (n = 41)	9		14	9	0.64	22.50 (32.20)	0- 80.56	0.54
	No (n = 7)	2	1	1	3		30.32 (71.32)	0- 93.75	
Type of Care (n = 48)	Private (n = 2)	1	1	0	0	0.45	13.33 (n/a)	0- 26.67	0.09
	Govt. (n = 44)	10	8	15	11		24.68 (30.71)	0- 93.75	
	Overseas (n = 2)	0	1	0	1		13.26 (n/a)	0- 26.06	
First Treatment (n=48)	Non-medical (n = 8)	1	2	1	4	0.12	34.21 (33.26)	0- 71.32	0.20
	Non-specialist (n = 29)	8	3	11	7		26.67 (35.85)	0- 93.75	
	Specialist (n = 11)	2	5	3	1		8.33 (25.60)	0- 44.69	
Definitive Care (n = 48)	Non-medical (n = 9)	2	1	1	5	0.36	37.40 (53.10)	0- 93.75	0.43
	Non-specialist (n = 10)	3	2	4	1		17.83 (37.78)	0- 56.02	
	Specialist (n = 29)	6	7	10	6		26.06 (31.88)	0- 80.56	

7.1.4.3 Initial care

Half of the participants who had non-biomedical healthcare treatment (i.e., seen by a neighbour or traditional healer), developed severe contractures; by comparison, only 1/11 participants seen initially at a specialist burn service developed a severe contracture. Only one participant who received non-biomedical healthcare initially had no contracture (Table 7-5).

Figure 7-3: BCSC and first healthcare presentation



Participants whose first place of care was a specialist burn centre had notably less loss of movement (median loss 8.33%), than those receiving non-medical care (median loss 34.21%) or non-specialist care (median loss 26.67%) (Table 7-5). However, these apparent differences in outcomes did not reach statistical significance.

7.1.4.4 Definitive care

Although participants accessing specialist care for initial care had least movement loss, this was not the case with respect to place of definitive care. Those who had definitive treatment in non-specialist centres had least loss of movement (median loss 17.83%); participants having definitive care in a

specialist centre had the second highest loss of movement across the groups (median loss 26.06%). Only one participant who had definitive care in a non-specialist centre had a severe contracture. However, differences in outcomes between specialist/non-specialist care groups were not statistically significant (Table 7-5).

Participants without any contracture were all admitted to definitive care either on the day of or day after the injury. Those who did not receive any care on the day of injury all had contractures but the time to definitive care was not statistically significantly related to contracture outcome (Table 7-5).

7.1.4.5 Length of stay

LOS was longest, with the widest range, in participants with moderate contractures (median 10 weeks) and shortest (median 6 weeks) in those without contractures. These differences were not statistically significant.

7.1.4.6 Discharge against medical advice

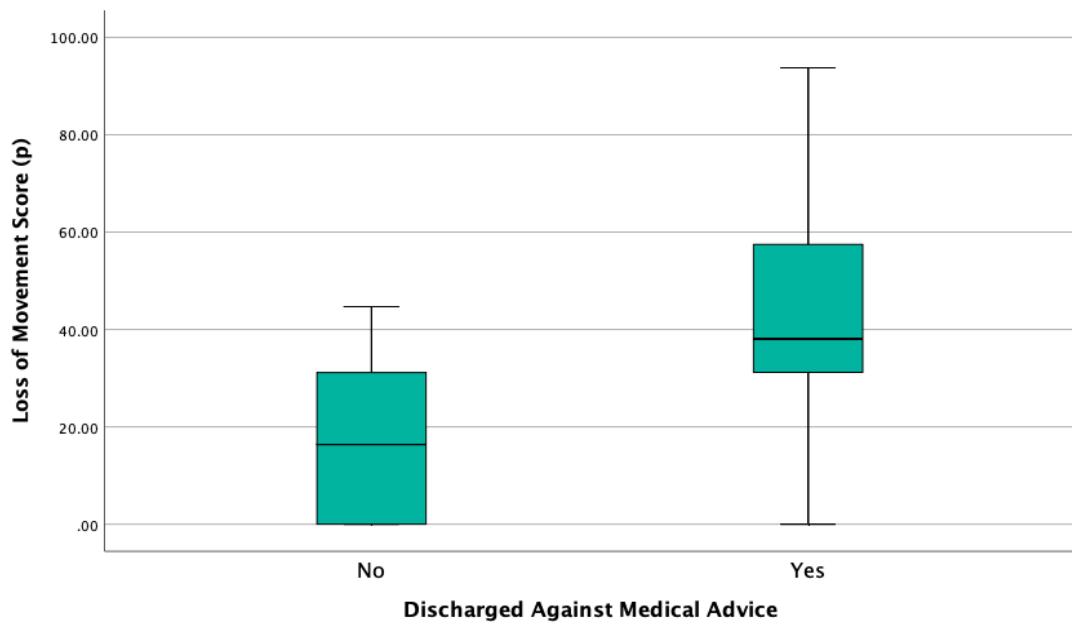
More participants who were discharged against medical advice had severe contractures (7/11), compared to those who did not self-discharge. Only one participant who took self-discharge did not develop a contracture, compared with 9/31 in the medically discharged group. Table 7-6 shows contracture outcomes by type of discharge. The differences observed were statistically significant (Chi Square = 16.45, df = 3, p = <0.01). There were more than expected severe contractures in participants who had been discharged against medical advice (Standardised Residual = 3).

Participants who self-discharged had significantly greater movement loss (median loss 38.07%) than those who were medically discharged (median loss 16.36) (Figure 7-4); this was statistically significant (Mann Whitney=58.5, p<0.01) (Table 7-6).

Table 7-6: Healthcare access factors: Duration of hospital stay, follow-up and costs

Risk Factor		Severity Classification - BCSC					LMSp		
		None	Mild	Mod	Severe	p	Median (IQ)	Min-Max	p
Length of Stay (weeks) (n =40)	Median (IQ) Min-Max	6 (10.3) 1 - 25	7 (6.5) 2 - 16	10 (10.5) 3 - 24	8.5 (11.4) 1 - 14	0.41			0.53
Non-medical discharge (n=42)	Yes (11)	1	2	1	7	<0.01**	38.07 (32.07)	0-93.75	<0.01**
	No (30)	9	7	13	2		16.36 (31.76)	0-44.69	
Follow-Up (n = 48)	Yes (26)	6	6	11	3	0.10	18.88 (33.49)	0-56.02	0.11
	No (22)	5	4	4	9		32.01 (38.66)	0-93.75	
Time to first follow-up (days) (n = 26)	Median (IQ) Min-Max	14.50 (13) 7 - 60	11 (13) 7 - 36	15 (23) 7 - 30	7 (367) 7 - 84	0.76			0.65
Follow-up visits (n = 26)	Median (IQ) Min-Max	6 (8) 1 - 20	11 (56) 3 - 120	5 (3) 1 - 20	1 (3) 1- 4	0.04*			0.01**
Cost of care (in '000s BDT) (n = 36)	Median (IQ) Min-Max	50,42,86 (65,00,00) 10,000- 100,00,00	30k (25,10,000) 25,000 – 150,00,00	30k (33,75,00) 10,000 – 150,00,00	35k (644,1250) 10,000 – 200,00,000	0.91			0.38

Figure 7-4: LMSP and discharge against medical advice



7.1.4.7 Follow-up

Contracture development did not appear to be related to whether participants had any follow-up or not (Table 7-6). Participants who did not have any follow-up had a greater loss of movement (median LMSP 32.01%) than those who did have follow-up (median LMSP 18.88%), but this difference was not statistically significant. Time to first follow-up also did not statistically significantly affect contracture outcomes.

Participants with mild contractures (n=6) had a median of 11 follow-up visits but those with severe contractures (n=5) had a median of only 1 follow-up; this difference was statistically significant (Kruskal Wallis = 29, df 3, p=0.04). A statistically significant relationship also existed between LMSP and number of follow ups ($\text{Rho} = 1.000, p=0.01$) (Table 7-6).

7.1.4.8 Cost of care

Costs of care are shown in BDT in Table 7-6 and were converted to GBP. Participants without any contractures had spent most on their care

(median 504,286 BDT, equivalent to £4,499), but those with severe contractures also had high expenditure (median 350,000 BDT equivalent to £3,107). There was no statistically significant relationship between cost of care and contracture outcome.

7.1.4.9 Summary of healthcare access risk factors

Participants who self-discharged against medical advice had statistically significantly worse contracture outcomes than those who were medically discharged. Low number of follow-up visits was also statistically significantly associated with more severe contracture outcomes. No other healthcare access risk factors had any statistically significant impact on contracture severity.

7.1.5 Medical / Surgical Treatment Risk Factors

7.1.5.1 ITU or HDU stay

There was no statistically significant difference in contracture outcome between participants admitted to ITU and those who were not, but participants not admitted to ITU had greater loss of movement than those who were. Although participants with severe contractures had the longest ITU stays and those with mild contractures had the shortest, contracture outcomes were not statistically significantly associated with ITU LOS (Table 7-7).

7.1.5.2 Skin grafting

There was no statistically significant difference in contracture severity between participants who had been grafted and those who had not. Observed differences in LMSp between groups was remarkably small; median LMSp was slightly lower in grafted participants than in those without grafts. The range of loss of movement was wider in the non-grafted group than the grafted group (Table 7-7).

Table 7-7: Treatment risk factors: Medical and surgical

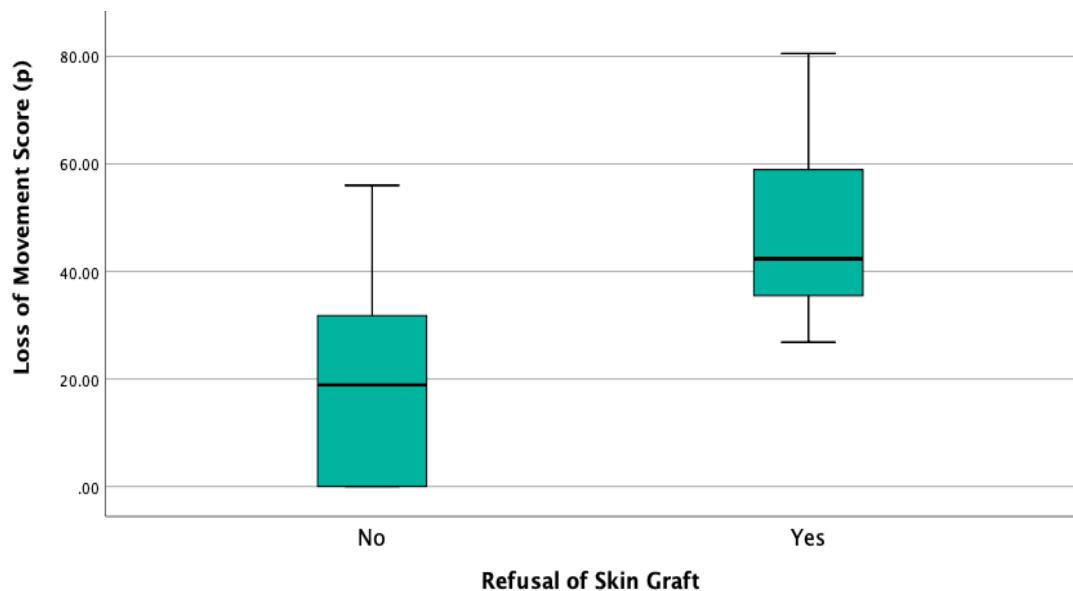
Risk Factor		Severity Classification - BCSC					LMSp		
		None	Mild	Mod	Severe	p	Median (IQ)	Min-Max	p
ITU stay (n=48)	Yes (13)	4	2	5	2	0.68	14.17 (28.60)	0-80.56	0.12
	No (35)	7	8	10	10		30.32 (31.25)	0-93.75	
Time in ITU (days) (n=12)	Mean (SD) Min - Max	28.75 (14.36) 10-45	5 (1.41) 4-6	38.50 (24.13) 2-74	51 (55.15) 12-90	0.18			0.10
Escharotomy (n = 46)	Yes (3)	1	1	1	0	0.88	8.33	0-15.29	0.13
	No (43)	10	8	14	11		26.85 (31.23)	0-93.75	
Skin graft (n = 48)	Yes (20)	5	3	9	3	0.28	22.74 (33.91)	0- 58.92	0.32
	No (28)	6	7	6	9		24.68 (31.26)	0-93.75	
Time to first graft (n=20)	Median IQ Min - Max	8.70 (13.3) 1.5-24	4 (4) 4-5	6 (7.5) 3-16	4 (4) 2-4	0.46			0.43
Refusal of skin graft (n=36)	Yes (6)	0	2	1	3	0.054	42.35 (30.98)	26.85- 80.56	<0.01**
	No (30)	8	6	13	3		18.88 (32.25)	0-56.02	

Time to first graft also did not statistically significantly affect contracture severity assessed by BCSC or LMSp (Table 7-7). However, the longest times to first graft and the widest variation in time to first graft were seen in participants without contractures; this is contrary to what might have been expected, as late grafting might be expected to result in more severe contractures.

7.1.5.3 *Refusal of skin graft*

In participants who refused a graft, every joint at risk developed a contracture; 27% of those who agreed to skin grafting had at least one joint at risk which did not develop a contracture. This difference was close to statistical significance (Chi Square = df = 7.71, p = 0.054). For LMSp, the difference between these two groups was highly significant (Mann Whitney = 16, p=<0.01). Participants who refused an offered skin graft had statistically significantly greater loss of movement across all joints at risk (median loss 42.35%) than those who accepted a skin graft (median loss 18.88%) (Table 7-7 and Figure 7-5)

Figure 7-5: LMSp and refusal of skin graft

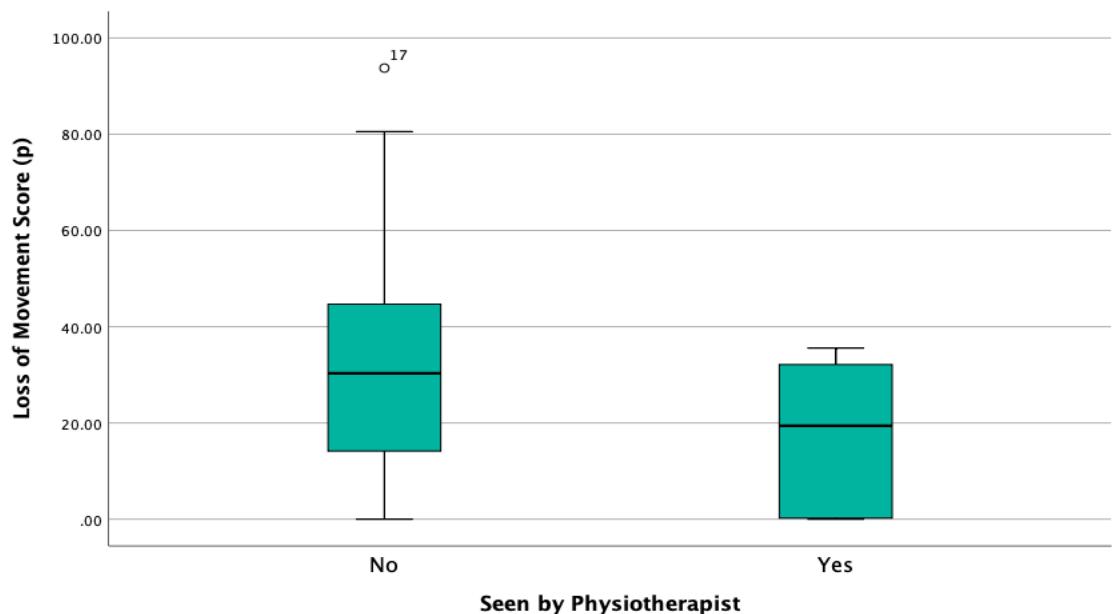


7.1.6 Rehabilitation Treatment Risk Factors

7.1.6.1 Physiotherapy Input

Similar numbers of participants who did and did not have physiotherapy had no contractures. Only 3/12 participants with severe contractures had seen a physiotherapist (Table 7-8). For BCSCp, there was no statistically significant difference in contracture severity between participants who did or did not see a physiotherapist, however those who were seen by a physiotherapist had notably less movement loss by LMSp than those who did not (Table 7-8); this difference was close to statistical significance (Mann Whitney=184, p=0.052).

Figure 7-6: LMSp and physiotherapy input



There were no significant differences between outcome groups with respect to physiotherapy input received. Notably, the number of physiotherapy sessions made no significant difference to BCSC or LMSp outcomes, although LMSp was extremely small in the group seen by a physiotherapist >20 times (median loss 0.23%) compared with those seen only once (median loss 26.38%) (Table

7-8). Values for the severe contracture group (n=3) are not reported in Table 7-8 as only one participant reported treatment time (10 minutes).

Table 7-8: Rehabilitation variables

Risk Factor		Severity Classification - BCSC					LMSp		
		None	Mild	Mod	Severe	P	Median (IQ)	Min-Max	P
Physio input (n =48)	Yes (19)	5	5	6	3	0.68	19.42 (33.70)	0- 35.56	0.052
	No (29)	6	5	9	9		30.32 (32.70)	0- 93.75	
Time to first physio (weeks) (n = 19)	Mean (IQ) Min - Max	45 (102) 8-120	30 (52) 2 - 60	63 (127) 12-195	74 (37.07) 20 - 91	0.43			0.90
Physio frequency (n = 18)	Once	1	1	4	0	0.35	26.38 (27.56)	0 – 34.13	0.09
	1-7x	1	1	1	1		13.88 (29.41)	0 – 35.52	
	7-20x	0	1	0	1		21.20 (-)	6.85- 35.56	
	>20x	3	2	1	0		0.23 (28.43)	0- 33.73	
Place of physio (n = 48)	No physio (29)	6	5	9	9	0.06	30.32 (32.70)	0- 93.75	0.09
	Inpatient (3)	0	0	3	0		33.73 (-)	33.70- 34.13	
	Outpatient (7)	3	1	3	0		8.33 (22.22)	0- 30.53	
	Both (9)	2	4	0	3		8.33 (30.86)	0- 335.56	
Physio time to treat (n = 18)	Median (IQ) Min - Max	20 (39) 1-40	7 (88) 1-160	1 (8) 1-30	4.50 (n/a) 2-7	0.43			0.76
Treatment time (minutes)	Median (IQ) Min - Max	20 (43) 10-60	10 (19) 5-30	7.50 (9) 0-10		0.15			0.13

7.1.6.2 Therapy Interventions

Various therapy interventions were examined against participant outcomes by BCSCp and LMSp Table 7-9. Of these, only pressure therapy had a statistically

significant effect on outcome by LMSp. No interventions were statistically significant by BCSCp outcome.

Table 7-9: Therapy interventions

Risk Factor		Severity Classification - BCSC				P	LMSp		P
		No	Mild	Mod	Severe		Median (IQ)	Min-Max	
Splinting (n =48)	Yes (14)	3	3	7	1	0.20	24.28 (32.83)	0- 93.75	0.71
	No (34)	8	7	8	11		17.50 (31.79)	0- 35.56	
Effective Splinting (n=48)	Yes (6)	2	3	1	0	0.13	17.50 (32.82)	0- 35.56	0.09
	No (42)	9	7	14	12		24.78 (32.83)	0- 93.75	
Exercise (n =48)	Yes (27)	6	6	10	5	0.63	17.33 (33.27)	0- 80.56	0.90
	No (21)	5	4	5	7		33.70 (39.79)	0- 93.75	
Positioning (n =48)	Yes (9)	4	4	8	3	0.53	17.33 (33.27)	0- 58.92	0.18
	No (29)	7	6	7	9		30.32 (38.92)	0 – 93.75	
Pressure (n=48)	Yes (17)	6	4	5	2	0.30	13.73 (26.37)	0- 36.15	0.01**
	No (31)	5	6	10	10		31.81 (32.19)	0- 93.75	
Effective Pressure (47)	Yes (6)	2	3	1	0	0.13	3.65 (27.63)	0- 30.53	0.09
	No (42)	9	7	14	12		26.46 (29.75)	0- 93.75	
Scar massage (n =48)	Yes (22)	5	3	11	3	0.07	20.96 (28.70)	0 – 44.69	0.10
	No (24)	5	6	4	9		32.01 (45.87)	0- 93.75	

7.1.6.3 Splinting

Half of the participants who had a splint still developed a moderate contracture, but almost 92% severe contractures were in the non-splinted group. Participants who had been splinted had slightly more movement loss than those who had not, which was surprising, but there was no statistically

significant difference between splinted and non-splinted groups for BCSC or LMSp (Table 7-9).

7.1.6.4 Effective splinting

None of the participants with severe contractures had effective splinting, but the majority without contractures also did not have effective splinting. Participants who had effective splinting had slightly less movement loss, but there were no significant differences in BCSC or LMSp between those who had effective splinting and those who did not (Table 7-9).

7.1.6.5 Exercise

LMSp suggested that participants who were instructed on exercise had lost less movement than those who were not, but this difference was not statistically significant (Table 7-9).

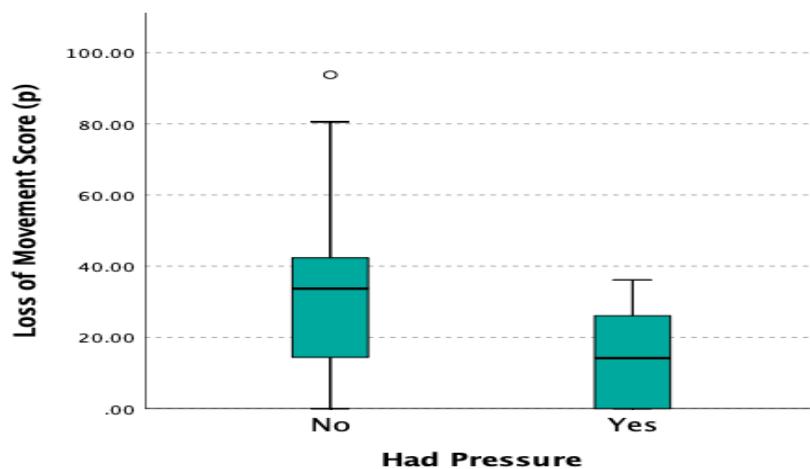
7.1.6.6 Positioning

Most participants with severe contractures had no positioning, but 7/11 participants who did not develop a contracture also had no positioning. Contracture severity measured by LMSp suggested that those who had positioning had less movement loss than those who did not have positioning, but this was not statistically significant (Table 7-9). It was not possible to determine how many participants had effective positioning.

7.1.6.7 Pressure treatment

By BCSCp, almost 2/3 of participants who did not have pressure treatment had moderate or severe contractures while 10/17 (59%) of those who did have pressure had no, or only mild, contractures; these differences were not statistically significant. However, LMSp was statistically significantly lower in participants who had pressure than in those who did not (Mann Whitney=139, p=0.01) (Table 7-9, Figure 7-7).

Figure 7-7: LMSp and pressure therapy



7.1.6.8 Effective pressure

Participants with effective pressure were a small group ($n=6$) but they had a very low LMSp (median loss 3.65%) compared to the no pressure group (median loss 26.46%), although this difference was not statistically significant (Table 7-9).

7.1.6.9 Scar massage

There was no difference in outcomes between those having or not having scar massage (Table 7-9).

7.1.6.10 Summary of Rehabilitation Treatment Risk Factors

Most participants were not seen by a physiotherapist, but physiotherapy input did not have a statistically significant impact on contracture outcome.

Although not statistically significant, there was a consistent pattern that participants who had received a therapy intervention had less movement loss than those who did not receive any intervention. The only exception to this was splinting; participants who were splinted had greater movement loss than those who were not. However, those with effective interventions compared to

non-effective interventions (splinting and pressure) had better movement preservation than those who did not have effective interventions.

The only therapy intervention which had a statistically significant impact on loss of movement was pressure therapy. Participants who had pressure treatment had statistically significantly less movement loss than those who did not; whether the pressure was deemed effective or not had no statistically significant bearing on movement loss, but the number of participants who had effective pressure was small.

7.1.7 Participant Awareness and Opinion

7.1.7.1 Awareness of the term contracture and contracture severity

Participants who had heard the word contracture were equally represented in each contracture severity group (Table 7-10). BCSCp outcomes were not affected by whether participants had heard of contractures, but LMSp was considerably lower in participants who knew the word contracture.

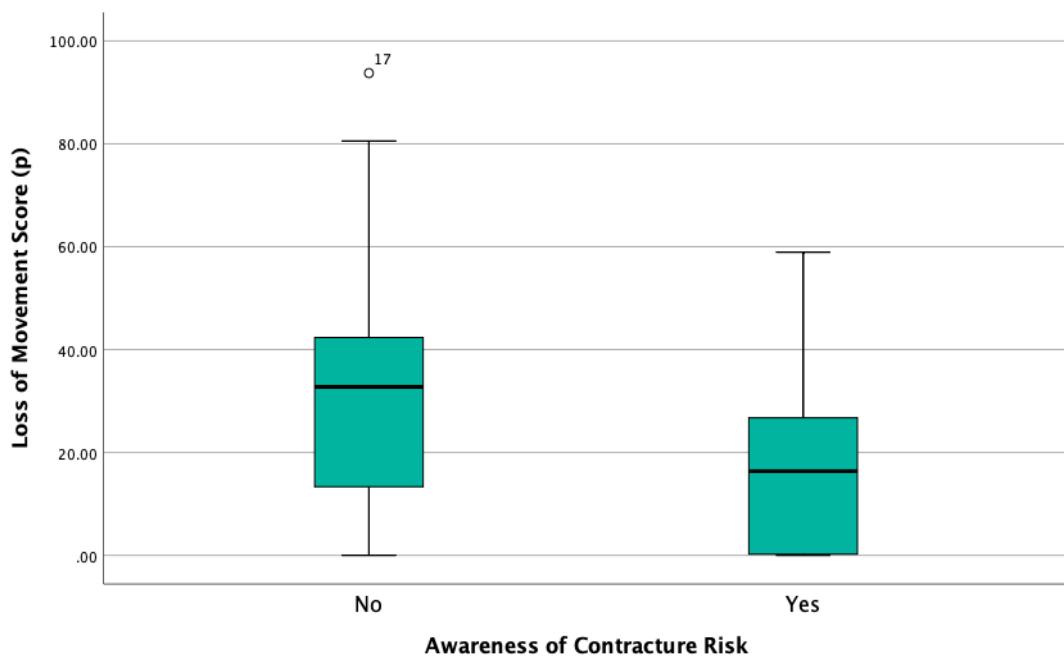
Table 7-10: Participant Awareness

Risk Factor		Severity Classification - BCSC					LMSp		
		None	Mild	Mod	Severe	p	Median (IQ)	Min-Max	p
Aware of term for contracture (n=47)	Yes (12)	3	3	3	3	1.00	17.35 (33.22)	0- 58.92	0.36
	No (35)	8	7	11	9		26.85 (30.65)	0- 93.75	
Aware of risk of contracture formation (n = 47)	Yes (28)	5	7	4	3	0.10	16.36 (IQ=26.85)	0- 58.92	0.03*
	No (19)	5	3	11	9		32.73 (IQ=30.60)	0- 93.75	

Participants who did not know that a contracture could develop after a burn injury had more moderate or severe contractures (20/28) than those who were aware of the risk (7/19), but this was not statistically significant.

However, there was a statistically significant difference in LMSp between participants who reported they were aware of the risk of contracture development and those who were not. Participants who were aware of the risk lost significantly less movement across their joints at risk (median loss 16.36%) compared to those who were not aware of the risk (median loss 32.73%) (Mann Whitney = 164, p = 0.03) (Table 7-10).

Figure 7-8: LMSp and awareness of contracture risk



7.1.7.2 Patient opinions

Participants were asked why they thought they had or had not developed a contracture; responses are reported in Table 7-11.

The only preventive factors proposed by participants and not already identified from the literature review or clinician interviews were knowing the doctor and God's help.

Table 7-11: Reasons participants believed they did or did not develop a contracture

Reasons Given for Developing Contracture	No. of Times Reported
Lack of proper treatment (2 specifically believed they would not have developed a contracture if they had gone to DMCH)	9
Unable to wear the splint or pressure garment or exercise given because of discomfort / pain	6
Too much pain	5
Due to the burn injury	4
Lack of funds	3
Lack of positioning and desire to stay in a position of comfort due to pain	3
Skin tightening	3
Burn happened as a child and therefore body grew but not scar	2
Due to having a skin graft	2
Lack of awareness or education about a burn injury	2
Lack of physiotherapy	2
Did not listen to doctor's advice	1
Dressings too tight	1
Extra growth of skin	1
Infection	1
Long healing time	1
Poor nursing care	1
Reasons Given for NOT Developing Contracture	No. of Times Reported
Strict adherence to doctors' orders	3
Having physiotherapy	3
Use of pressure garments	2
Early application of splint	1
Having a skin graft	1
Wounds not so deep	1
Being known to the doctor	1
God's help	1

7.1.8 Summary of Whole Person Analyses

Overall, eight risk factors were significantly linked to contracture severity at whole person level, as assessed by at least one outcome measure (either BCSCp or LMSP) but only three factors statistically significantly for *both outcome measures* at whole person level.

i) **Employment status:**

- Participants who were unemployed had significantly more severe contractures and greater loss of movement than those who were employed
- Participants who were in non-manual employment had less severe contractures and less loss of movement than those in other categories

ii) **Discharge against medical advice:** Participants who self-discharged had significantly more severe contractures and greater loss of movement than those who did not

iii) **Follow-up:** Participants with fewer follow-up visits had greater contracture severity and loss of movement

Statistically significantly associated with contracture severity by *BCSC only*:

- Age: Older age at the time of burn and time of interview was associated with more mild contractures
- Burn depth: Full thickness burns were associated with more severe contractures.

Statistically significant risk factors by *LMSP outcome only* were:

- Refusal of skin graft: Participants who refused a skin graft had greater movement loss
- Pressure therapy: Participants who had pressure treatment had less movement loss than those who did not

- iii) **Participant awareness:** Movement loss was significantly lower in participants who knew about the risk of contracture from the time of burn than in those who did not know

Significance levels for these factors are summarised in Table 7-12.

Table 7-12: *Statistically significant risk factors for burn contracture severity at person level*

Risk Factor	BCSC	LMSp
Unemployed (employed/unemployed)	0.04* (CS)	0.01** (MW)
Unemployed vs non manual	0.03* (CS)	0.02* (KW)
Discharged against medical advice	<0.01** (CS)	<0.01** (MW)
Low frequency of follow up	0.04* (CS)	0.01** (SR)
Older age at time of burn	0.01** (KW)	NS
Older age at time of interview	0.02* (KW)	NS
Full thickness burn	0.02* (CS)	NS
Refusal of skin graft	NS	<0.01** (MW)
Issued a pressure garment(s)	NS	0.01** (MW)
Participant awareness of risk of burn contracture formation	NS	0.03* (MW)

(Statistical tests used CS = Chi-Square, KW = Kruskal-Wallis, MW = Mann-Whitney, SR = Spearman's Rho, NS = not significant)

7.2 JOINT RISK FACTORS AND OUTCOMES

This section presents the analyses of selected joint-specific factors on the presence and severity of contracture at the joints at risk. At joint level, six treatment risk factors were examined as well as the anatomical location of the joint itself.

7.2.1 Joints Included

Of the 126 joints at risk of contracture, most (107/126, 85%) were in the upper body (neck, shoulders, elbows, wrists). The lower limb joints (hip, knee, ankle) included only 2 hips at risk. Due to small numbers, hips were excluded from analysis of risk factors by joint location.

7.2.2 Treatment Risk Factors Examined

The six treatment risk factors selected for analysis were skin grafting, wound healing time, infection, splinting, positioning and pressure treatment. These factors were explored previously at whole person level but also require examination at individual joint level. Each risk factor was analysed for effect on the number and severity of contractures, the latter determined by BCSCj and LMSj for each joint. Data were not available on every risk factor for all joints at risk.

7.2.3 Treatment Risk Factors and Contracture Frequency

Analyses of the selected risk factors against overall contracture outcomes showed that there was no significant difference between contracted and non-contracted joints with respect to skin grafting, infection, healing time, splinting or positioning.

However, of 46 joints receiving pressure, only 33% developed contractures, but 61% of 80 joints not receiving pressure developed a contracture; this

difference was highly statistically significant (Chi Square = 9.59, df = 1, p = <0.01).

Joints which received pressure (n=46) were also more likely to have been grafted (27/46) than those that did not (23/78); this difference was statistically significant (Chi Square = 10.26, df = 1, p = <0.01). There was no significant difference in the proportions of grafted and un-grafted joints that were splinted. Seventeen of 24 grafted joints were positioned, compared with only 11/61 un-grafted joints. Grafted joints were statistically significantly more likely to have been positioned (Chi Square = 9.61, df = 1, p = <0.01) (Standardised Residual = 2.1). These results suggest there may be a link between receiving skin grafting and the use of other therapy interventions, perhaps indicating that these joints were treated in a specialist centre, which itself may improve outcome.

Wounds that were grafted took a median of 16 weeks (IQ 14, min 4, max 104) to heal, which was very similar to healing time in the wounds that were not grafted (median healing time 16 weeks, IQ 13, min 5, max 52). Infection occurred in 19/45 joints that were grafted (42.2%) and in 19/49 joints that were not grafted (38.8%); this difference was not statistically significant.

7.2.4 Treatment Risk Factors and Contracture Severity

Table 7-13 shows how the selected joint treatment risk factors affected contracture severity. Non-contracted joints (n=64) are excluded from this analysis.

Table 7-13: Treatment risk factors and contracture severity

Risk Factor		BCSCj				LMSj		
		Mild	Mod	Severe	p	Mean (SD)	Min - Max	p
Grafted (n=63)	Yes (26)	8	15	3	0.03**	41 (23)	3- 89	0.25
	No (37)	15	10	12		40 (29)	7- 100	
Time to Heal (weeks)	Mean (SD) Min- Max	21.48 (14.48) 4-52	18.40 (10.80) 6-52	20.57 (24.94) 8-104	0.60			0.34
Infected (n=44)	Yes (18)	8	8	2	0.72	41 .27)	3- 100	0.93
	No (26)	9	12	5		40 (27)	7- 89	
Splinted (n=63)	Yes (13)	4	8	1	0.17	45 (16)	27-71	0.95
	No (50)	19	17	14		38 (29)	3-100	
Positioned (n=56)	Yes (13)	5	23	14	0.07	37 (19)	7-100	0.26
	No (43)	14	16	13		47 (29)	7-100	
Pressure (n=63)	Yes (15)	8	5	2	0.29	34 (24)	3-71	0.07
	No (48)	15	20	13		43 (27)	7-100	

While the application of pressure statistically significantly decreased the frequency of contracture, pressure did not affect contracture severity. Joints which received pressure had fewer severe contractures and lower mean loss of movement than joints which did not receive pressure, but these differences were not statistically significant.

The only statistically significant result for all treatment risk factors analysed for severity was in the BCSCj of grafted joints (Chi Square = 6.82, df = 2, p = 0.03). Grafted joints were less likely to develop severe contractures. LMSj did

not indicate any significant difference in mean ROM lost between grafted joints and those not grafted (Table 7-13).

7.2.5 Anatomical Location of Joint at Risk

Contracture outcomes were also examined by anatomical location of the joints at risk.

7.2.5.1 Contracture severity at different anatomical joints

Table 7-14 shows the contracture frequency and severity for different joint locations. The neck and shoulder had the highest contracture rates, while the wrist and knee were least likely to contract.

Excluding the hip (n=2), the difference between whether a joint contracted or not across the six joint locations included in the analysis was statistically significant (Chi Square = 32.94, df = 5, p = <0.01). Based on Chi Square distribution, statistically more than expected necks (Standardised Residual = 2.0) and shoulders (Standardised Residual = 2.3) developed contractures. There were statistically fewer than expected wrists without contractures (Standardised Residual = 2.2).

Table 7-14: BCSCj severity by joint location

Joint	None	Mild	Moderate	Severe	Contracture Rate (%)
Upper Body					
Neck (18)	3	5	8	2	83
Shoulder (30)	6	6	12	6	80
Elbow (26)	18	5	1	2	31
Wrist (33)	24	5	2	2	27
SUBTOTAL (107)	51	21	23	12	52
Lower Body					
Hip (2)	1	0	0	1	50
Knee (11)	8	3	0	0	27
Ankle (6)	2	1	0	3	67
SUBTOTAL (19)	11	4	0	4	42
TOTAL	62	25	23	16	51

7.2.5.2 Contracture severity at different anatomical joints

The BCSCj contracture severity of different anatomical joints at risk also differed across different anatomical joints (Table 7-14).

There was no statistically significant difference between joints in the upper or lower body with respect to contracture severity (Chi Square = 0.73, df = 1, p = 0.44). Severity of contracture by joint location was close to statistical significance but did not quite reach it (Chi Square = 18.21, df = 10, p=0.053). The knee had more mild contractures than expected (close to cut off Standardised Residual = 1.8) and ankles had more than expected severe contractures (Standardised Residual = 2.1).

There was no statistically significant difference between joints in the upper or lower body or across all joint locations with respect to LMSj.

7.2.6 Treatment Risk Factors and Joint Location

Since anatomical location of the joint appears to be a risk factor for contracture, the previous analyses of other risk factors may have been confounded by the effect of joint location. To investigate this further, the frequency of the selected interventions was analysed by joint location in 124 joints (excluding hips, n=2) (Table 7-15).

Only a small number of joints were splinted (23/103), however the difference between rates of splinting in different joints was statistically significant (Chi Square = 23.88, df = 5, p = <0.01). Apart from the neck, the majority of joints were not splinted, but more necks than statistically expected were splinted rather than not splinted (Standardised Residual = 2). Based on the treatment factors analysed there were no other statistically significant results for impact of joint location on distribution of treatment risk factors. Differences in the rates of pressure treatment at different anatomical joints were almost

statistically significant ($p=0.052$), with the neck and shoulder being least likely to receive pressure treatment; this is unsurprising due to the difficulties of applying pressure garments at those areas.

Table 7-15: Frequency of intervention by joint location

Risk Factor	N	Neck	Shoulder	Elbow	Wrist	Knee	Ankle	p
Grafted (n=124)	Yes (50)	7	17	13	10	3	0	0.06
	No (74)	11	13	13	23	8	6	
Splinted (n=124)	Yes (21)	10	4	4	2	1	0	<0.01**
	No (103)	8	26	22	31	10	6	
Positioned (n=113)	Yes (28)	5	8	7	5	3	0	0.48
	No (85)	12	20	15	26	6	6	
Pressure (n=124)	Yes (46)	5	7	14	15	5	0	0.052
	No (78)	13	23	12	18	6	6	
Healing Time (Weeks)	Median (IQ) Min-Max	14 (17) 6 - 52	13 (11) 5-52	16 (12.45) 6-52	16 (14) 4-104	20 (20) 8-52	16 (25) 4-36	0.93
Infection (n=88)	Yes (33)	8	8	7	8	4	0	0.25
	No (55)	6	16	11	16	6	6	

These results show that the inherent risks of different anatomical joints along with variable distribution of interventions across different joints could alter the apparent significance of an intervention on outcome. This recognition prompted further analysis of treatment factors by individual joint location.

Treatment factors were analysed for individual joints excluding the hip. For the shoulder, 11/17 grafted joints were contracted, and all 13 un-grafted joints were contracted. This was statistically significant (Chi Square = 5.74, df = 1, $p = 0.02$), but for every other joint location, skin grafting had no statistically significant effect on contracture frequency. This shows that although skin grafting was not found to be significant when all anatomical joint outcomes were considered together, it was a significant factor at the shoulder (lack of grafting likely to result in more contractures).

None of the other treatment factors had any statistically significant relationship with contracture outcome (presence/absence) at any other joint. This included pressure treatment, which was originally significantly associated with fewer contractures when all joints were considered together.

The small numbers in this study precluded further analysis of every selected treatment risk factor against severity of contracture outcome (BCSCj and LMSj) at each anatomical joint location.

7.2.7 Summary of Joint Analyses

This section reports the results of analyses of 126 individual joints in the study. The majority of joints did not have any treatment intervention (graft, splint, positioning or pressure). Healing times for wounds over joints were long and the infection rate was high (41%), which in addition to lack of grafting, may explain long healing times. Therapy interventions were limited and often deemed ineffective; they were instituted late and for limited duration.

There was no consistent pattern in the effect of treatment risk factors on whether a joint developed a contracture or not, nor on the severity of any resulting contracture. Although statistically significant results indicated pressure reduce the likelihood of a joint contracture, and grafting decreased the severity of contracture. The most significant finding was that different anatomical joints have inherent and statistically significantly different risks of contracture. Necks and shoulders were significantly more likely to contract, whereas wrists were significantly less likely to contract.

This finding potentially confounds risk factor analyses in groups of joints at different anatomical locations. In this study, joints which had effective pressure were more likely not to develop a contracture when all joints were analysed together, but when individual joints were examined separately,

pressure had no significant effect on outcome at any joint. When all joints were considered together, skin grafting did not appear to protect against contracture but did reduce contracture severity. However, when joints were examined individually, grafting was a protective factor for contracture development at the shoulder but not at any other joints. The numbers of individual anatomical joints in this study were too small to allow further analyses, but this finding may have important implications for past and future risk factor studies.

Table 7-16 summarises the main findings of the analyses of risk factors at joint level.

Table 7-16: Summary of risk factors at joint level

Risk Factor	Joints Analysed	Finding	p
Anatomical joint location	All excluding hip (n=124)	Neck and shoulder more likely to contract, wrists less likely to contract	<0.01**
Skin grafting	All joints	Grafted joints less likely to be severely contracted	0.03*
	Individual anatomical joints (n=124)	Only grafted shoulders less likely to contract	0.02*
Infection	All joints	No relationship with contracture development	NS
	Individual anatomical joints (n=124)	No relationship with contracture development	NS
Wound Healing	All joints	No relationship with contracture development	NS
	Individual anatomical joints (n=124)	No relationship with contracture development	NS
Pressure therapy	All joints (Joints receiving pressure less likely to contract	<0.01**
	Individual anatomical joints (n=124)	No relationship with contracture development	NS
Splinting	All joints	Necks more likely to be splinted, but no effect on outcome	<0.01**
	Individual anatomical joints (n=124)	No relationship with contracture development	NS
Positioning	All joints	No relationship with contracture development	NS
	Individual anatomical joints (n=124)	No relationship with contracture development	NS

8 DISCUSSION

8.1 INTRODUCTION

The aim of this study was to identify risk factors for burn contractures in LMICs, which could subsequently inform strategies to mitigate contracture prevalence and severity. The study was designed to identify LMIC risk factors from existing literature, views of experienced LMIC clinicians and the results of a cross-sectional observational study of burn survivors attending a specialist Burns Centre in Dhaka, Bangladesh.

The specific objectives of the thesis have been achieved:

- 1) The wide-ranging literature review revealed limited robust evidence on contracture risk factors pertaining to LMICs
From the literature review and clinician interviews, a detailed framework of potential contracture risk factors was devised and converted to a semi-structured interview tool for the primary data collection in Bangladesh
- 2) Appropriate methods of measuring contractures were selected for the low-resource environment of the study. Contracture presence and severity were classified using categorical and continuous scores, at both whole person and individual joint level. This allowed objective stratification of study participants and joints into standardised groups for comparisons of exposures to different risk factors. A new categorical severity score (BCSCp) based on participants' worst contractures was utilised, in addition to a novel risk-adjusted score derived from movement loss at all joints at risk (LMSp), for analyses of whole person risk factors.
- 3) A unique Data Collection Tool incorporating the interview guide and measurement protocol was designed for the main study, along with a

purpose-built ODK platform for data collection and organisation; both are available for use by future researchers.

- 4) Primary data were collected and analysed from 48 participants recruited in the selected LMIC setting, enabling identification of several statistically significant risk factors for contracture, at both whole person and joint levels, as well as some patterns and trends which may be worthy of further investigation. Some of the statistically significant risk factors identified have not been previously considered by HIC authors, including refusal of skin graft, discharge against medical advice, lack of outpatient follow-up and participant awareness of risk of contracture.

Overall, this study has confirmed that the risk factors for contracture in LMICs differ from those recognised in HICs and should be investigated separately.

Additional findings are:

- There is a lack +/- delay of specialist treatments for burn care in LMICs which are considered standard in HICs, such as intensive care, skin grafting, early and regular physiotherapy input and interventions such as splinting, exercise, and pressure therapy.
- There is a lack of planned follow-up or adjustments to rehabilitative treatment in LMICs.
- Access to appropriate treatment, from acute burn through rehabilitation, is often determined by patients' awareness, social status and ability to pay, rather than their clinical needs.
- There are methodological inconsistencies in all studies (both from HICs and LMICs) including varying definitions of contracture and joints at risk, differing times and methods of measurement, mixed populations of participants, joints and burns and non-standardised care, all of which make identifying genuine risk factors in HICs and LMICs very difficult.

Therefore, although the research question '**What are the risk factors for burn contracture formation in a low-income setting?**' could not be fully answered by this study, the importance of the question has been validated and this work has laid a foundation for future studies of risk factors for contracture in LMICs.

8.2 EXISTING KNOWLEDGE

Previous publications on risk factors from HICs focus largely on burn- or treatment-related factors whereas LMIC papers and clinicians emphasise the importance of non-medical factors affecting health outcomes especially income and access to care, education, and unemployment i.e., the social determinants of health. Between completion of the literature review in July 2019 and thesis submission in March 2022, several additional relevant papers have been published ($n=10$), which are summarised in Table 8-1. Five papers specifically addressed risk or predictive factors for contracture (Lensing et al., 2021; Meng et al., 2020; Tan et al., 2020; Yelvington et al., 2021; Zhu et al., 2021).

Only two new papers (both from HIC/UMIC) contributed any new risk factors not previously identified from the literature review. Lensing et al. (2021) found that the number of days of bedrest had the greatest impact on the risk of future contracture and that, at joint level, older age and greater weight gain also increased contracture risk. Zhu et al. (2021) demonstrated a higher risk in blue-collar workers, perhaps also indicating low income or educational status; these workers may also be at higher risk of severe burns from occupational exposures to hazardous materials.

Table 8-1: Relevant publications since July 2019 in chronological order

Article	Origin	Type of Study	Sample	Main Focus of Study
Meng et al. (2019)	Canada (HIC)	Systematic review	14 papers included	A systematic review of factors affecting contractures in children in LMICs
Tan et al. (2019)	China (UMIC)	Descriptive retrospective	108 adults treated in ICU for >50% burns	Factors affecting incidence and severity of contracture at 1 month in patients with burns >50% TBSA
Puri et al. (2019)	India (LMIC)	Retrospective observational	486 patients requiring contracture reconstruction	Presumed causes of contracture and preventive action needed at clinical and health system level
Lensing et al. (2020)	North America (HIC)	Descriptive observational	300 patients on ACT database (9 centres)	Factors affecting limitation of ROM in affected joints at hospital discharge
Zhu et al. (2020)	China (UMIC)	Retrospective cross-sectional observational	220,642 pts on national database	Prevalence and predictors of readmission for contracture over 5 years
Yelvington et al. (2021)	North America (HIC)	Retrospective observational	225 children with 1597 contractures	Severity of contracture at hospital discharge
Schouten et al. (2021)	Holland (HIC)	Prospective	117 patients, 353 operated joints	Changes in limitation of joint ROM over 12 months during healing of burns after acute surgical Rx
Botman et al. (2021)	Tanzania (LMIC)	Descriptive observational	67 (31 acute burns and 36 with contracture)	Factors contributing to delayed arrival of acute burn patients at tertiary centre and reasons why patients from hospital catchment still developing into severe contractures
Hendricks et al. (2021)	Tanzania (LMIC)	Prospective cohort study	44 patients, 115 joints	Effects of surgical contracture release on ROM, disability and quality of life
Iyer & Soletti (2021)	India (LMIC)	Descriptive	9 patient stories	Impact of contracture on psychosocial wellbeing

All four recent papers from LMICs commented on the lack of knowledge about contracture formation in such settings, supporting findings from the main literature review detailed in Chapter 2. Meng et al. (2020) found only 14 papers worthy of inclusion and commented that “there is a severe lack of information on what happens between the early phase (of a burn injury) and the late complication stage (contractures).... this disconnect makes any correlations between early burn care and late sequelae very difficult” (Meng et al., 2020, p. 1002). The shortage of LMIC input to existing published knowledge on risk factors for burn contractures concurs with the findings of the Lancet Commission on Global Surgery, which has highlighted a dearth of data from LMICs on a whole range of surgically correctable conditions (Meara et al., 2015).

Meng et al. (2020) identified a separate category of potential risk factors which they called ‘Environmental Factors’. These included limited system infrastructure (facility, personnel, rehabilitation) and distance to nearest health care facility; all these factors were cited in the clinician interviews as potential contributors to contracture in LMIC environments but do not normally feature in HIC publications.

For this present study, all potential risk factors which have been identified to date were considered, although several factors were not examinable in the present LMIC study setting. Reasons for exclusion include the lack of medical documentation, a relative lack of access to some surgical treatments and a general absence of specialist therapy inputs. Other risk factors were outside the scope of the study (such as system infrastructure) or not possible to ascertain accurately from participants. A few potential risk factors (e.g., poverty) were so prevalent in the study population that no differences existed between different outcome groups; in other cases (e.g., effective physiotherapy

interventions) too few of the study population were exposed to enable any conclusions to be drawn.

Nevertheless, this study evaluated 48 potential risk factors in 6 different categories and is believed to be the most wide-ranging study of LMIC contracture risk factors to date.

8.3 STUDY DESIGN

Although the best type of study to identify significant risk factors would be a prospective, controlled, and long-term follow-up investigation, this was not feasible in Bangladesh at present, because of the way healthcare is provided. Within the time and resources available for this project, a cross-sectional observational design was most appropriate and enabled initial exploration of many potential risk factors. Within the context, participants were the most comprehensive and reliable sources of data.

The interview questions used were designed to allow quantitative analyses of results rather than qualitative evaluation, although some qualitative information was obtained during the process. A quantitative approach was selected to facilitate comparison of outcome groups with respect to risk factors. This does not diminish the importance of patient experiences; the suffering experienced by contracture patients was clearly evident in the study participants and has been described by others (Iyer & Soletti, 2021; Hendricks et al., 2021).

In common with other authors, the present study elected only to include major joints. This does not imply that excluded joints (face, hands, feet) are of lesser importance; rather the additional number of joints and planes of movement would have exceeded the feasibility of this study. Similarly, a pragmatic decision was made to limit the planes of movement which were examined.

One important finding from the process of this study was how infrequently joints at risk of contracture were defined. In this retrospective study, without detailed documentation of the acute burn, a decision was made to define joints at risk from the observed degree of scarring across or adjacent to joints. Although subjective, this is a common method of assessment in clinical practice. However, it is recognised that the late appearance of a scar may not reveal the extent of tissue damage. This is particularly so in electrical burns, which may severely damage underlying tissue without notable skin scarring and were therefore excluded from the present study.

Variations in extent of scarring over or near a joint and the degree to which surrounding joints are involved means that not all joints are at the same risk, even in the same person. Furthermore, which joints, and which surface(s) are affected by any scarring (i.e., flexor, lateral or extensor surfaces) also alters the risk of contracture. Scarring on flexor surfaces is more likely to increase the risk of contracture formation (Schouten et al., 2021). The importance of defining a joint at risk of contracture and awareness of their heterogeneity has not yet been clearly articulated in the literature. Only four studies provided a definition for a joint at risk. Many studies did not report the numbers or locations of joints at risk. The recently proposed method of defining a joint at risk by extent of CFUs involved (Parry et al., 2019) may be more accurate but is much more difficult to do and requires direct observation of the acute burn or extremely detailed documentation which can be assessed later. From the CFU argument, joints adjacent to the joint at risk may also affect the risk and movement at each included joint.

It is also important to consider which risk factors operate at whole person level or only at individual joint level. This was the first study that differentiated risk factors at joint and person level and considered contracture severity at the

whole person and joint level. No LMIC study prior to 2019 examined risk factors at joint level and no HIC publications before 2021 examined risk factors at whole person level. Factors such as socioeconomic status, education, and residence location clearly affect the whole person and all their joints. Conversely, factors such as grafting, splinting and positioning are directly related to individual joints and not a whole person. Much of the confusion regarding risk factor significance may result from using inconsistent or inappropriate outcome measures. Whole person evaluations should preferably take account of all joints at risk, not just one affected joint. Many joint-specific factors require very detailed documentation to be accurately captured. As so many whole-person factors influence joint outcomes in LMICs, the current HIC focus on risk factors operating solely at joint level may not be as pertinent to LMICs. For completeness, both whole person and joint-specific factors were included in the present study.

8.4 OUTCOME MEASURES

The main outcome measure selected for this study was the presence or absence of a contracture, defined as a measured deficiency in ROM in a joint at risk when compared with accepted reference values for full ROM. While this is a conventional approach and as objective as it was possible to be, several aspects are worthy of discussion.

The first consideration is the increasing call, currently from HIC authors only, for functional measures of contracture rather than measured ROM. A deficiency in measured ROM does not necessarily signify any significant clinical problem. Further, in joints having more than one plane of movement, ROM deficiency in one plane may not always result in a functional deficit: patients can compensate for loss of ROM in one plane by altering how they complete certain functions.

Extensive work has been done recently to develop a core set of outcomes for burn injuries, to enable evaluation of interventions using outcomes which are important to patients as well as clinicians (Young, 2020). In this study, both burn patients and clinicians initially rated contracture highly as an important single outcome. However, patient consensus determined that lack of function was of greater importance than contracture. In the final stage of the Delphi process amongst clinicians, contracture fell below the cut-off for inclusion. Contracture as a single outcome did not appear in the final selection of seven core outcomes, although the consequence of a contracture could be reflected in the individual's ability to perform daily tasks (a final core outcome).

There is no doubt that appropriately selected, sensitive, valid, and reliable outcomes, such as those proposed by Young (2020), are vital in trials assessing the merits of interventions and perhaps even to evaluate quality of care in different centres. However, functional outcome of a joint after a burn is a consequence of many factors including age, co-morbidity, ethnicity, cultural habits, treatments, adaptability, and patient psychology. As such it is considered too complex a measure for use in LMIC risk factor studies at the present time. This study was focused on the impact of potential risk factors on contractures, rather than on the impact of contracture on the patient; simple measures of outcome severity at joints at risk were considered most appropriate for this study.

It was not feasible to measure ROM in every plane of movement for every joint in this study, so it is unknown if any ROM limitations were present in planes other than those selected for study. A further debate is whether active or passive ROM is preferable for measurement. In this study, passive ROM was selected after three active movements, but other authors believe that active ROM is more representative (Tan et al., 2021). There is no consensus in the

burn literature on whether range should be measured with passive or active movement. There is also no report on the number of movements on which measurement should be taken (joint movements may alter the ROM available). Both these factors are likely to affect the reported measurement(s) and could be important to standardise.

Whichever movements are measured, a reference range of normal ROM is required for comparison. Common to all contracture definitions based on joint measurement, is the assumption that standard reference ranges of ‘normal’ values for full ROM at each joint can be applied with confidence. However, there are ethnic and cultural variations in expected ‘normal’ joint mobility (Bashaireh et al., 2020), based on genetic factors and cultural habits. Populations in which sitting cross-legged is frequent even up to old age (e.g., for working and eating) are likely to have a much greater range of hip movement than is found in populations where normal sitting positions for work, eating or relaxing do not require any significant abduction or external rotation of the hip (Kumar et al., 2011).

The reference range of ‘normal’ ROM presented in the burn literature, is derived from predominantly Caucasian and western populations and may well be inappropriate for LMIC studies. Yelvington et al. (2021) stated, “It is important to recognize that the normal ROM values may not be universally consistent. Other sources may report different “normal” values for anticipated joint movements and defined normal ranges” (p432). For this present study, no appropriate reference ROMs were available, therefore the reference ranges used were not specific to the population being studied.

Whether a patient is observed to have a contracture or not is also dependent on the time of observation. In the present study, mean time from burn at the time of assessment was 2.5 years, which is much further along the contracture

maturation timeline than many other published studies of risk factors. Most HIC studies on contracture risk factors determined outcomes at acute hospital discharge, often as early as 21 days or sooner. This is not representative of the final outcome at 18-24 months, as has been demonstrated by Schouten et al. (2019 and 2021). Furthermore, many non-surgical therapeutic interventions which can affect outcome are only implemented after hospital discharge, making identification of risk factors for contracture even more complex. Even decisions on the need for surgical release of a joint (used by some as a definition of contracture) will vary depending on the timing of assessment. Much more work is required to standardise these definitions and time points of measurement to allow correct identification of risk factors and for comparison across studies.

Along with a clear definition of contracture, the present investigation also categorised contracture severity to facilitate comparisons of participants and joints with respect to potential risk factors. There remains no accepted classification of contracture severity (Schouten et al., 2021). Various methods have been used in the literature, ranging from subjective 'eyeball' assessment to detailed measurements; both categorical and continuous scales have been used. As different statistical analyses are required for categorical and continuous variables, utilisation of a simple categorical severity scale and actual ROM measurement (continuous data) allows more complex statistical tests to be employed when analysing risk factors (Agresti, 2013). Both categorical (BCSC) and continuous (LMS) measured were used in the present study.

It is acknowledged that factors other than loss of ROM may be equally or even more important in defining the severity of outcome from the patient's point of view. Thick and prominent skin bands, aesthetic appearance, pain or itch and

functional deficits may all be more important to patients than the range of joint movement which they can achieve. It is also apparent that different individuals may experience different impacts from the same measured degree of joint limitation; a mother who must prepare food, lift her child and clean the house usually requires a wider range of movement in her upper limb joints than a bus driver. Iyer and Soletti (2021) and Hendricks et al. (2021) have described how negatively and significantly contractures affect burn survivors in terms of self-worth, earning capacity and participation in family and social activities.

Although it is frequently used, one problem with the Schneider et al. (2006) categorisation scale, on which BCSCp/j is based, is that there is just one degree of movement between cut-off levels for each category, which could easily be a measurement error. Such mis-categorisations could easily over-estimate or undermine contracture severity and alter results of risk factor analyses. Additionally, joints with lower normal ROM (such as the neck, wrist, and ankle) require a smaller absolute loss of ROM to be categorised as severe, than do joints with greater ROM (such as the knee, shoulder, and elbow). Thus, measurement errors of even one degree may have a considerable effect on BCSC categorisation.

Both BCSC and LMS are derived from normal reference ROMs which are calculated from the neutral position, but in some severe contractures the neutral position is completely lost, and the effect of the contracture is to produce a measured ROM which is theoretically outside the normal range. Some examples of this were demonstrated with photographs in the Methods Chapter, where an observed ankle and wrist were contracted beyond the normal reference range of movement, meaning that any residual movement captured by the measurement protocol (in these cases dorsiflexion of the ankle

and flexion of the wrist) appeared to demonstrate greater than normal ROM. Therefore, without careful interpretation, contracture severity could be underrepresented. Such severe contractures are rarely seen in HICs (where all current contracture classifications originated), but this difference highlights the need for methods able to capture the range of contractures seen in LMICs.

Despite these drawbacks, the present study successfully utilised measured joint ROM to assign participants and joints to a BCSC category and calculate a proportional Loss of Movement Score for each joint at risk (LMSj). Determining an appropriate LMS for the whole person was more challenging. Although some published LMIC studies have examined contracture risks at person level, they do not provide methodological details on which joint, or contracture was used as the basis of the whole person analysis. Subsequently, Hendricks et al. (2021) used a person-level outcome for success of contracture release based on the worst and best functional ROM of any affected joint but did not consider the outcomes of other joints at risk.

As far as can be ascertained, this is the first study in which a risk-adjusted mean loss of joint movement score (LMSp) has been created to provide a continuous whole-person variable, incorporating ROM losses at all affected joints. This calculation uses the cumulative proportional loss of ROM at all affected joints divided by the number of joints at risk to give a mean proportional loss of ROM per joint at risk. This risk-adjusted method also takes account of the fact that different individuals may have different sized burns across different joints and therefore should allow risk factors other than the size and depth of multiple burns to be more readily identified.

It is acknowledged that both BCSCp and LMSp are still imperfect measures of whole person outcomes. Assigning a whole-person severity category based on a single contracture does not take account of how many other joints may have

been at risk and contracted, even if less severely than the worst. Similarly, using the average proportional loss of movement across all joints at risk (LMSp) produces a lower score than simply using measured loss of ROM at the worst joint to represent the whole patient. Additionally, neither BCSCp or LMSp takes account of the increasingly apparent risk variation between different anatomical joints, which has also not been considered in any other risk factor studies.

Although BCSCp and LMSp were determined quite differently, it was interesting to observe that they were quite closely, though not exactly, aligned for participants in this study. In evaluating risk factors, some patterns were significant for BCSCp outcomes but not for LMSp, and vice versa. At person level two risk factors were only statistically significant using BCSCp and 3 others were only statistically significant using LMSp. At joint level, no risk factors measured by LMSj were found to be statistically significant. This shows that although assessment of contracture severity by BCSCj is similar to that of LMSj, there are subtle differences between the two outcomes, probably because even one degree of movement loss can change BCSC categorisation. This demonstrates how important the choice of outcome measure is in determining the importance of any risk factor.

LMSj gives a more accurate description of actual loss of movement at a joint than simple severity classification (BCSCj). Some degree of approximation is inherent in categorisation and even small measurement errors can alter BCSCj, as described above. Depending on the purpose of the assessment, categorical scores may be easier to apply, but if more accurate determination of contracture severity is required (for example, following an intervention or for research purposes), then LMSj may be more pertinent. When evaluating risk

factors, LMSj and LMSp are probably more accurate and considerably easier to interpret.

Overall, it is important to remember that the outcome measures used to determine severity must be appropriate for purpose. For clinical decision-making or evaluating the effects of interventions, outcomes which focus on individual or worst joint severity, or loss of function at individual joints, may be appropriate. However, for risk factor analysis, it is essential to avoid inadvertent bias resulting from the use of outcomes inherently determined by the extent and location of the burn itself. In addition, burn survivors often have more than one joint at risk, and each of those joints may have received different treatments and had different outcomes, there is a need for a better method of describing whole person outcomes when more than one joint is involved. As interest in whole person risk factors is encouraged, perhaps new methods of determining whole person outcomes will emerge.

8.5 RECRUITMENT

The study participants were self-selected, as only individuals who sought healthcare during the study period were interviewed. Further, due to difficulties encountered in interviewing acute burn patients and measuring joints in a busy acute ward during the pilot study, the study was ultimately restricted to non-acute participants. Since few participants had no contractures, it cannot be considered truly representative of all burn survivors. Nevertheless, participants came from all over Bangladesh, had varying acute treatments and contractures of varying severity in many different joints; this range of experiences and outcomes enabled a wider range of potential risk factors to be explored.

Data were initially collected and processed from 56 participants, 8 of whom had to be excluded, leaving only 48 recruited participants and 126 joints for the final analysis. This was disappointing and fewer than the 60 participants planned. The study was not conducted at a time of year that could explain the lack of participants, such as harvest-time or a religious festival. It became apparent that most patients with contracture who attended during the study period (including those who were eligible and recruited for the study) received limited active treatment at their attendance and were not offered any date for contracture release. It is possible that this was a powerful and known disincentive for contracture patients to return, which could explain the low numbers of eligible participants. Every effort was made to recruit as many participants as possible, but the lack of any formal follow-up system meant that attendance was completely dependent on patients' will and resources, and possibly negatively affected by their low expectations for timely or effective interventions.

Additionally, as anticipated, patients without problems did not normally return to OPD. Only 4 participants did not have a contracture at any joint and 7 did not have a contracture at a major joint. Due to the low numbers of participants without contractures, it was not possible to examine risk factors for presence/absence of contracture at the whole person level, but both presence and severity of contracture were analysed for individual joints.

It was not uncommon for participants not to know their age, or for there to be inconsistency between medical documentation, relative or participant reports. Due to the enthusiasm of local doctors to maximise recruitment into the study, some participants were encouraged to report an age that would enable inclusion (i.e., ≥ 18 years), despite being younger. Some interviews had to be discontinued when it became apparent that the participant was underage.

It was sometimes difficult to identify participants who had any previous reconstruction of a major joint. Participants sometimes confused acute surgery with later reconstructive surgery, or release of a joint with skin grafting. Due to lack of burn knowledge, interpreters were sometimes unable to make this distinction. Several participants were initially included, but during the interview it became clear that their joint had been reconstructed. Electrical burns were also excluded at the data cleaning stage.

8.6 RISK FACTORS

8.6.1 Demographic Risk Factors

Demographic risk factors that were statistically significant for the severity of contracture were the age of the participant and at the time of burn and at the time of interview. Participants who were older at presentation were more likely to have a mild contracture than any other severity classification. This may just reflect that those with less severe disabilities may not seek attention early. Although not statistically significant, the most severe contractures were seen in younger participants at the time of burn and interview. Participants who were oldest at time of injury were statistically significantly more likely to have mild contractures. This finding was consistent with the literature. Age at burn is commonly cited as a risk factor for contracture and was found to be statistically significant in some HIC studies; the risk was predominantly highest for younger ages (Gangemi et al., 2008; Kraemer et al., 1998; Kidd et al., 2013), although older age was also identified as a statistically significant risk factor (Goverman et al., 2017a; Lensing et al., 2021). Both LMIC risk factor studies identified younger age as statistically significant for burn contracture/disability (Agbenorku, 2013; Forjuoh et al., 1996). In studies it is not always clear whether the reported age is at the time of burn or at the time of evaluation. Age at time of injury is most probably a more relevant risk factor

than age at presentation or data collection. However, time since injury is important, as it influences the observed outcome (Schouten et al., 2019; Schouten et al., 2021) as well as the range of risk factors which can be examined.

Although there were similar numbers of males and females in the study population, burns are reported to be more common in females in Bangladesh (Bailey et al., 2019; Mashreky et al., 2008 a and b). In other LMIC studies that include patients with contracture, the higher proportion of participants were female (Puri et al., 2019; Botman et al., 2021; Kim et al., 2012; Agbenorku, 2013; Hendriks et al., 2021; Muguti & Fleming, 1992). Why men and women were equally represented in the present study population is uncertain and may be a consequence of the small numbers. Alternative explanations are that females have less overall access to healthcare than males in Bangladesh, or that contractures in women are considered less important.

In this present study although not statistically significant, women had greater movement loss than men (+16.8% higher median loss of movement). This could be because contractures have to be more severe in women to justify the costs and travel times incurred, or because they sustained more severe burns e.g., from cooking injuries, or because their early care was incomplete.

Gender has been commonly explored as a risk factor in the literature. Gender has only been found to be statistically significant in HIC literature to date; females are usually reported to have a higher risk (Gangemi et al., 2008) although one study reported men at higher risk and found female gender to be protective (Goverman et al., 2017b). Agbenorku (2013) included gender in his analysis of risk factors, but it was not reported to have any significant impact on disability in that population.

The long distances travelled by most participants to reach DMCH suggest that there is a lack of facilities for specialist burn care and contracture release elsewhere in Bangladesh. Given that burns are so common in LMICs, especially in rural areas (Bailey et al., 2019; Meshreky et al., 2008a), this is an issue for burn care provision and outcomes. Many participants lived in rural areas (27/48); similar findings have been reported in other studies. In the systematic review by Meng et al. (2020), four studies documenting where children with contractures lived found that 60-80% of them were from rural or impoverished areas.

Although not statistically significant, participants living furthest from DMCH (both in time and kms), had the most severe contractures and more movement loss. More participants who lived in urban areas compared to rural did not develop a contracture and those from rural areas had more severe contractures; however, LMSp scores were similar between rural and urban dwellers. Place and type of residence may be determined by socioeconomic status or vice versa; those in rural areas of Bangladesh are generally poorer and of lower socioeconomic status than those in urban areas (He et al., 2017). In this study, participants living in rural areas generally had lower monthly household incomes (median 11,260 BDT/month) than those living in urban areas (median 39,000 BDT/month). As with gender, the pattern of more severe contractures occurring in those living further from DMCH could be because the injury has to be more severe to justify the trip for appropriate treatment.

No HIC studies have identified location of residence or distance from healthcare as risk factors for burn contracture, nor have these factors been included as study variables. Forjouh et al. (1995) analysed residence (urban, semi-urban or rural) as a risk factor for disability, but it was not found to be statistically significant. Botman et al. (2021) and Hendriks et al (2021) found

average travel times of 2 and 3 hours respectively for patients requiring contracture release in Tanzania. In this present study, participants had an average single journey time of 3.89 hours and a mean of 110 kms to travel to DMCH. These journey times and distances illustrate how difficult it is for patients to access specialist burn care in Bangladesh and how committed they must be to do so.

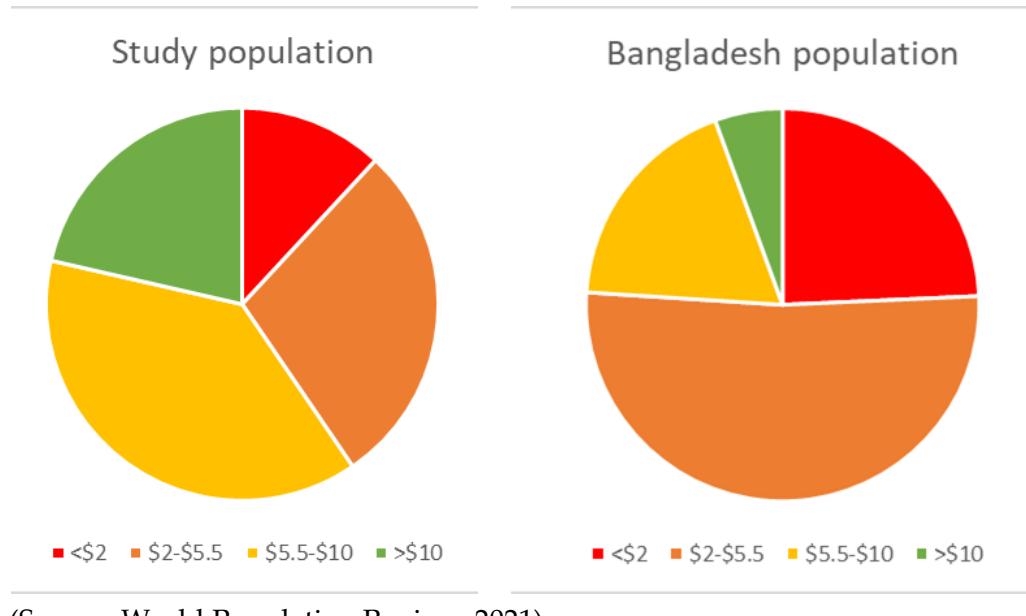
8.6.2 Socio-Economic Risk Factors

Socioeconomic status is a subset of demographics, but rarely features in HIC studies. The social determinants of health underly many health inequalities in communicable and non-communicable diseases (Commission on Social Determinants of Health, 2008), but are as yet not rarely considered as risk factors for burn contractures. Socioeconomic factors are more commonly cited in LMIC publications and were also highlighted as being potential risk factors in the clinician interviews. Agbenorku's (2013) LMIC study identified some socioeconomic factors (family support and economic impact on the family) as having a statistically significant impact on burn contracture.

Almost 80% of participants in the present study were living on < US\$10/day. Although those with the most severe contractures had the lowest household incomes per month, it is unsurprising that no significant difference in contracture outcome was found in relation to income, as poverty was so widespread in the study population. This is consistent with burns being an injury predominately suffered by the poor (Bailey et al., 2019). Although most of the study population were living on <US\$10/day, overall a lower proportion were living in extreme poverty (<US\$1.9/day according to the World Bank defintion of extreme poverty) or on less than US\$5.5/day than is the case across Bangladesh as a whole (Figure 8-1). Since there is no reason to suppose that poorer patients do not sustain burns, this may reflect that patients need better

incomes to even consider contracture treatment; it is possible that the poorest contracture patients simply could not afford to seek care.

Figure 8-1: Comparative income distribution between the study population and Bangladesh as a whole



(Source: World Population Review, 2021)

Data on estimated costs of care were available from 30 participants in this present study, there was no statistically significant relationship between cost of care and contracture outcome. Botman et al. (2021) in a study examining barriers to surgical care for burn patients in Tanzania defined 'catastrophic expenditure' on healthcare as out of pocket cost equal to or greater than 10% of an individuals yearly expenditure. Although annual income is not the same as yearly expenditure, when the estimated costs of care were compared to participants' annual income, in only 3/30 cases did the costs represent less than 10% of annual income. In fact, the estimated costs of care to date (in participants who had not yet had their contractures released) ranged from 3.3% of annual income to 125 times the annual income. Mean expenditure on care was 12.09 times the annual income and the median was 1.4 times the annual income. Taking these data into account, it may be surmised that only

the most highly driven participants with considerable family financial support were attending DMCH during the study period to seek treatment.

The only socioeconomic risk factor which was statistically significant for the severity of contracture (for both measures of contracture severity) was employment; more severe contractures and more movement loss were found in the unemployed. Agbenorku (2013) did examine occupation as a risk factor, but it was not found to be statistically significant. Zhu et al. (2021), in a study from China, found that blue-collar workers had a higher risk of readmission for contracture after burns. No HIC studies have explored employment status as a risk factor for burn contracture, although there is evidence that contractures themselves limit the ability to return to work (Katsu et al., 2021; Pham et al., 2020). Therefore, it is not clear whether employment status is itself a risk factor or whether it is the consequence of the presence and severity of contracture.

Employment status may be a proxy for socioeconomic status and may affect and reflect household income. In this present study, unemployed participants had more movement loss than those in manual or non-manual jobs. This finding may reflect income levels. Non-manual workers often earn more than the other categories, which in turn may facilitate better healthcare and outcomes in countries like Bangladesh, where care is dependent on patients' ability to pay.

In this present study, the majority of participants were literate. As far as is known, no other study has examined literacy as a risk factor for contracture, although it has been cited as a putative risk factor and was reported by the clinicians interviewed in this study. Botman et al (2021) found a similar proportion of patients who were illiterate in their descriptive study of 31 burn patients attending for reconstruction in Tanzania.

Two HIC studies have included education levels as a potential risk factor. Richard et al. (2017) included level of education in an adult population and Gorga et al. (1999) included the level of education of parents and children in a paediatric study as variables in their studies. Forjouh et al., (1996) examined levels of maternal education in relation to his paediatric population; children with educated mothers were at lower risk of burn related disability. In this present study, 51% had secondary or tertiary level education. In the study by Botman et al. (2021), most patients had no or only primary education; in the current study, 51% had secondary or tertiary level education.

Higher levels of literacy and/or education may result in or from higher socioeconomic status and may also affect adherence to treatment; as such they would be expected to protect against contracture. The finding in this present study that literate participants and those with the highest level of education had greatest movement loss was unexpected and hard to explain. It could be a consequence of the small study population, or it may be that those who were more educated, and more literate were more likely to present for care than those of lower socioeconomic status and educational level.

It is therefore possible that literacy and education levels may be important risk factors for contractures in LMICs, although they have been only minimally examined in HIC literature. Without a prospective study of all burn survivors, it is not possible to be conclusive.

A summary of current knowledge on key demographic and socioeconomic risk factors is provided in Table 8-2 below.

Table 8-2: Summary of demographic risk factors identified from the literature review, clinician interviews and primary data collection

Risk Factor	Source and Details		
Demographics	Existing Literature from HIC/LMIC	Clinician Interviews	Present Study
Gender	HIC&LMIC: Men* and women* both cited as being more at risk but more studies suggest females at higher risk	☒	NS pattern: women had more severe contractures than men
Place of residence	LMIC: Time and distance from healthcare/rural or urban residence	✓	NS pattern: most severe contractures and more movement loss with increased distance from DMCH. Rural area participants had more severe contractures than urban dwellers.
Ethnicity	HIC: Hispanics and blacks at higher risk*	✓	Unable to examine, no variation of ethnicity in population
Age at time of burn	HIC&LMIC: Younger age, children at higher risk* HIC: Older age more risk at joint level*	☒	Participants with mild contractures were older at time of burn* NS pattern: youngest participants had the most severe contractures
Age at assessment	HIC (adults and children assessed separately and LMIC (younger population)	✓	Participants with mild contractures were older* Youngest participants had most severe contractures
Low socio-economic level	LMIC: Low socioeconomic status	✓	Only examined through income and employment status: none/low employment status increased severity of contracture and loss of movement *, income NS but majority poor
Occupation	UMIC: Blue collar workers*	☒	Unemployed had more severe contractures than employed* and more severe contractures than non-manual workers*
Poverty	LMIC: Poverty	✓	NS: Majority living on <US\$10/day, 12% in extreme poverty

* = statistically significant, NS=not significant, ✓= mentioned only, ☒= not examined

Table 8-2: (continued)

Risk Factor	Source and Details		
	Existing Literature from HIC/LMIC	Clinician Interviews	Present Study
Demographics			
Unable to pay for care / lack of govt. support	LMIC: Perceived inability to pay	✓	NS, but 11 cited inability to pay as reason for not seeking care or not continuing care. Catastrophic expenditure on care in 27/30, up to x125 participants income/year
Illiteracy	LMIC: Illiterate	✓	Unexpected pattern NS: literate participants had more severe contractures and more movement loss than non-literate
Education level	HIC& LMIC: No or lower educational level	✓	Unexpected pattern NS: participants in/completed tertiary education had most severe contractures
Maternal education	LMIC: Lack of maternal education*	☒	☒
Lack of family support	LMIC: Lack of family support*	✓	No difference observed, all participants had close family support
Lack of female autonomy	☒	✓	☒

* = statistically significant, NS=not significant, ✓= mentioned only, ☒= not examined

8.6.3 Other Patient Risk Factors

Several diverse patient characteristics unrelated to demographic or socioeconomic descriptors or to the burn injury have been cited or claimed to be actual or potential risk factors for contracture. Some are of biological/genetic origin (tendency to scar), some are medical (co-morbidities, muscle weakness), some relate to mental capacity (intelligence/learning disability/psychiatric or psychological problems), some are behavioural issues and others derive from cultural beliefs.

Very few participants reported any co-morbidities. Presence of co-morbidities is cited in HIC literature and was found to be a statistically significant risk factor for contracture formation in one study (Goverman et al., 2017b). The lack of comorbidities may reflect the young age of the present study participants or could be due to selection bias; LMIC burn survivors with comorbidities may be more likely to die or less likely to seek treatment.

The only risk factor in this category which was statistically significant in this present study was lack of knowledge/awareness of the risk of contracture. Participants who were aware of the risk of contracture formation had significantly less movement loss than those who were not. It may be that this knowledge heightened participants desire to do everything to avoid contracture, including adhering to recommended treatments, exercises, and follow-up. The fact that patients with more awareness of the development of contractures had better movement is both interesting and important; giving patients this knowledge requires relatively little cost and time. This underlines the importance of increasing awareness of burn sequelae in all stakeholders (especially patients, their families and hospital staff), which was highlighted by Puri et al. (2019) as a key role for centres of excellence. Table 8-3 summarises current knowledge on key individual patient risk factors.

Table 8-3: Summary of patient characteristic risk factors identified by source

Risk Factor	Source and Details		
	Existing Literature	Clinician Interviews	Present Study
Patient Characteristics			
Biology of patient/tendency to scar	☒	✓	☒
Co-morbidities	HIC: Presence of co-morbidities*	✓	No pattern: very small number with co-morbidities 4/48
Psychiatric history	HIC	✓	☒
Psychological problems /Low mood	HIC: Psychological problems but NS	✓	No reported psychological problems
Learning impairment	HIC	✓	☒
Lack of intelligence	LMIC	✓	☒
Fear/anxiety	HIC & LMIC	✓	Some participants reported fear of surgery (n=3)
Ignorance/lack of awareness about burn injury, treatment or risks	LMIC	✓	Participants who did not know that they could develop a contracture had greater movement loss *
Muscle weakness	HIC	✓	☒
Positive toxicology screen/alcohol or drug abuse	HIC	☒	☒
Lack of personal hygiene	☒	✓	☒
Cultural beliefs	☒	✓	☒

* = statistically significant, NS=not significant, ✓= mentioned only, ☒= not examined

8.6.4 Burn Injury Factors

Flame burn has been cited as a statistically significant risk factor for burn contracture in HIC literature (Hop et al., 2014), but in this study it was not significant, probably because so many participants had flame burns and the group without contractures was so small. The majority of LMIC studies describing characteristics of patients with burn contractures report flame burn as the most common aetiology (Agbenorku, 2013; Botman et al., 2021; Hendriks et al., 2021; Kim et al., 2012; Muguti & Fleming, 1992; Puri et al., 2019; Ringo & Chilonga, 2014).

Higher TBSA is the most frequently reported statistically significant risk factor for burn contractures in HIC publications (Gangemi et al., 2008; Godleski et al., 2008; Goverman et al., 2017a and b; Hop et al., 2014; Kidd et al., 2013; Kraemer et al., 1988; Schouten et al., 2019 Schneider et al., 2006). The study by Forjuoh et al. (1996) reported “body surface area burned” (p. 82) as a statistically significant factor in his study of disability but presented no definition of the term or any supporting data. TBSA was examined by Agbenorku (2013) but was not found to be statistically significant. In the systematic review by Meng et al. (2020), TBSA was identified as a risk factor. However, no data was presented to support how or why this conclusion had been drawn from the literature reviewed, as none of the papers included had identified TBSA as a factor associated with contracture.

TBSA was not a statistically significant risk factor in this study, but the pattern observed was opposite to usual expectations, in that those participants with lower TBSA had more severe contractures and greater loss of movement. One possible explanation for this pattern is that in LMICs it is likely that patients with larger TBSA (certainly those >40%) are much less likely to survive, and therefore do not present with contractures. It is notable that the two

participants with the largest TBSA burns in the present study (60% TBSA) were both treated overseas where specialist facilities were immediately available. It is also possible that in LMICs, those with smaller TBSA may think the burn is less serious and because of the direct and indirect expenses of seeking care, choose not to access specialist care. It is also important to note that accurate TBSA in the present study was very difficult to ascertain, due to the lack of medical documentation of the acute burn.

Depth of burn is consistently cited to be a risk factor for burn contracture and has been found to be statistically significant in both HIC and LMIC studies. In HIC literature the depth of burn is often not examined as a risk factor directly but is inferred if the area was grafted i.e., a grafted burn is considered synonymous with a deep burn. Several studies cite the presence or TBSA of a skin graft, deep burns and/or TBSA of full thickness burn as statistically significant risk factors (Gangemi et al., 2008; Goverman et al., 2017a, 2017b; Kraemer et al., 1988; Schneider et al., 2006; Schouten et al., 2019).

LMIC studies reporting the characteristics of reconstructive patients mostly do not report the depth of the original burn, probably because of limited data, as was found in this study. Agbenorku (2013) and Forjuoh et al. (1996) reported depth of burn (described as “involved skin removal” Agbenorku, 2013, p. 82) and full thickness burns (Forjuoh et al., 1996) to be statistically significant risk factors. It is likely that both depth and TBSA of burn are risk factors in both HICs and LMICs, but current literature has not yet provided sufficient evidence from LMIC studies.

In this present study, the depth of burn had a statistically significant impact on contracture severity at person level; full thickness injuries were more likely to develop a severe contracture. Although this observation was expected, it needs to be treated with particular caution because documentary evidence of

burn depth was lacking, and limited data were available from only 20/48 participants.

Effective first aid practices of immediate and prolonged skin cooling are considered to reduce the final depth of a burn (Fadeyibi et al., 2015). In this study, the definition of appropriate first aid was difficult to achieve in a LMIC context as it included immediate attendance at a healthcare facility, however this is consistent with other definitions of first aid (World Health Organisation, 2011). Although relatively few participants had received appropriate first aid by this definition, the majority had applied cold water for some duration; it is unsurprising that there was no evidence that appropriate first aid was related to contracture severity. In a study conducted in Nigeria by Fadeyibi, (2015) only 29% had appropriate first aid (defined as lavage with water only). For many LMIC patients, especially in rural areas, finding clean water for immediate and prolonged cooling of a burn is a challenge.

Other burn factors which have been shown to affect contracture presence and severity did not do so in this study, including inhalation injury, wound healing time and infection. Their lack of association with outcome in the present study could be due to inadequate definition or documentation of the risk factor itself, or simply to the small size and self-selection of the population studied.

Inhalation injury is cited as a statistically significant risk factor for contracture (Schneider et al., 2006), perhaps because it is often associated with major burns and prolongs patient immobility in an ITU setting. None of the LMIC studies include this variable either as a descriptor or in analysis. In LMIC settings, access to intensive care and ventilation is very limited and patients with significant inhalation injury may die before any contracture becomes apparent. In this present study, a surprising number of participants (11/48)

claimed to have had an inhalation injury, but this was substantiated by medical records in only three.

Burn-related factors may have more influence in contracture development in HIC settings because burn care is more standardised. Long healing times are unusual in HICs and rarely reported, possibly because of all the ameliorating adjuncts of care such as effective pain relief, infection control, grafting, splinting, and exercise. Only one HIC study considered healing time (Gangemi et al., 2008).

In LMICs, healing times are far more variable. Agbenorku (2013) found that patients with wounds that took more than 30 days to heal (no definition of healing was given) were five times more likely to result in an impairment than those who healed in 1-4 days. Unexpectedly, in the present study there was no significant relationship between healing times and whether joints got contracted or the severity of contracture. Additionally, grafted, and un-grafted joints took very similar lengths of time to heal; this cannot be explained by graft failure, as only 3 patients reported graft failure. However, overall healing times were generally longer (mean 19 weeks to heal) than would be expected in HICs.

One reason for delayed healing is infection. Forjuoh et al., (1996) cited wound infection as a statistically significant finding in his study, but did not present any data to support this, nor provide any definition of infection. In this present study, infection was determined from participant report or/and microbiological culture recorded in medical documentation. Participants with infection had slightly less movement loss than those without, but it would be expected that wound infection would slow healing time and therefore increase scarring.

The anatomical location of a burned joint can itself affect the risk of contracture, as has recently been shown by Schouten et al. (2021). A number of studies have shown upper limb joints to have a significantly higher contracture rate (Agbenorku, 2013; Forjuoh et al., 1996; Gangemi et al., 2008; Hop et al., 2014; Kidd et al., 2013; Kraemer et al., 1998). Consistent with these reports, the majority of contractures in this present study were in the upper limb. Only one study (Lensing et al. 2020) found a statistically significant higher rate of contracture in lower limbs at hospital discharge, but as demonstrated by Schouten et al. (2019) this early assessment is unlikely to represent the final contracture outcome.

The frequency of observed contractures in an uncontrolled study such as this one is dependent on the frequency with which different joints were at risk, however neck and shoulder joints at risk were statistically significantly more likely to be contracted in the present study and wrists significantly less likely to contract. When wrists (and ankles) were contracted, the mean LMS_j indicated more severe movement loss. These results were skewed by the fact that a few wrists and ankles were so contracted as to have been considered 100% loss of movement, which did not occur at any other joints.

That different joints have different inherent contracture rates may have been recognised previously, but the importance of this observation was not recognised or incorporated in previous studies of other contracture risk factors. This makes comparisons between studies very difficult and has major implications for interpretation of risk factor studies which include multiple joint locations. In future, it will be necessary to control for these inherent joint risks by analysing different anatomical joints separately. Unfortunately, the small numbers in the present study precluded such detailed analysis, although a limited evaluation of treatment factors showed how the observed

significance of grafting and pressure changed when only one joint (the shoulder) was included.

In summary, although burn injury factors are some of the most cited risk factors for burn contracture in the literature, in this study their role appeared more limited, with only joint location and burn depth being statistically significant. This may be because accurate assessment of many burn factors relies heavily on detailed medical documentation at the time of initial injury.

In LMIC environments, where medical records are often poor and burn databases are not available, retrospective studies based largely on patient recollections are unlikely to produce reliable data on initial burn factors such as TBSA, burn depth, inhalation injury, wound healing times or infection rates. It is therefore not possible to state with certainty that burn risk factors do not have an impact on contracture outcomes in Bangladesh; only better information about the nature of the initial injury can answer this question.

It is also possible that the impact of burn injury and treatment factors is 'hidden' under more powerful factors such as joint location and uncontrolled (compared to the HIC settings) influences such socioeconomic status and access to the healthcare system through the continuum of burn recovery.

A summary of current knowledge on key burn injury risk factors is shown in Table 8-4 below.

Table 8-4: Summary of burn injury risk factors identified by source

Risk Factor	Source and Details		
Burn Injury Factors	Existing Literature	Clinician Interviews	Present Study
Cause of burn	HIC: Flame burn*	☒	No pattern, majority had flame burn (36/48)
Mechanism of injury	HIC & LMIC	☒	☒
First aid	LMIC: Lack of first aid*	✓	No pattern only but 20/45 had appropriate first aid
Location of Burn	HIC: Head/neck/axilla/hand*; Burn over joint*; LL burns*; UL vs LL* LMIC: head/neck/trunk*, axilla/head/neck*	✓	Neck and shoulder more likely to contract than not* Wrist less likely to contract*
TBSA of injury	HIC: Higher TBSA*	✓	Unexpected pattern NS: participants with lower TBSA had more severe contractures
Depth of Burn	HIC&LMIC: Deep/full thickness burns*	✓	Those with FTB had more severe contractures *
TBSA of FTB burn	LMIC: Higher % TBSA FTB*	☒	☒ Data not available
CFU involvement	HIC: Greater FTB involvement of CFUs*; Location and higher number of CFUs*	☒	☒ Data not available
Presence of oedema	HIC	☒	☒ Data not available
Time to heal	HIC&LMIC: longer time to heal*	✓	No pattern observed
Inhalation Injury	HIC: presence of inhalation injury*	☒	No pattern observed (11/48 claimed to have had inhalation injury)
Delayed wound healing / wound closure	HIC&LMIC: Longer healing time*	✓	No pattern observed: wound healing time had no influence on contracture presence or severity at person or joint level

* = statistically significant, NS=not significant, ✓= mentioned only, ☒= not examine

Table 8-4: (continued)

Risk Factor	Source and Details		
Burn Injury Factors	Existing Literature	Clinician Interviews	Present Study
Low albumin and protein levels	☒	✓	☒ Data not available
Weight loss/gain	HIC: Greater weight gain*	☒	Data collected but very subjective, considered unsuitable for analysis 27/48 reported lost weight during wound healing period
Tension over wounds	HIC	✓	☒ Data not available
Infection	LMIC: Infection*	✓	No apparent influence on presence or severity of contracture at person or joint level
Pain	HIC and LMIC	☒	Data collected but very subjective, considered unsuitable for analysis
Pain threshold	HIC: Low pain threshold	✓	☒ Data not available
Thick scars	HIC and LMIC	☒	☒
Neuropathy	HIC: Neuropathy*	✓	☒ No participants with this risk factor
Hypertrophic ossification	HIC: presence of HO	☒	☒ No participants with this risk factor
Amputation	HIC: Amputation*	☒	☒ No participants with this risk factor

* = statistically significant, NS=not significant, ✓=mentioned only, ☒=not examined

8.6.5 Treatment Factors

8.6.5.1 Medical/Surgical Treatment Factors

Most of the risk factors for contracture discussed in HIC publications relate to medical or surgical treatments. Surprisingly, only one medical/surgical treatment factor was statistically significant as a risk for contracture in this present study. This factor - refusal of skin graft - has not yet been reported in HIC or LMIC literature as a risk factor. Refusal of a skin graft may have a direct clinical impact on the severity of any ensuing contracture, in that if a graft was offered it is likely the wound was deep, which often results in greater scarring and contracture. Graft refusal could be linked to low socioeconomic status and income (unaffordability of prolonged/surgical treatment), low educational level, or fear of treatment. In the present study, 11 patients refused grafts, giving a variety of reasons for doing so, including cost, fear and (in 2 female participants) the need to care for young children at home. It is unlikely that in a HIC healthcare setting, these concerns would have been allowed to prevent a necessary surgical treatment without considerable counselling and encouragement.

In the remaining medical/surgical treatment factors which were explored, there were some unexpected observations, although none were statistically significant. As with inhalation injury, participants who had an ITU stay had less severe contractures than those who did not. In contrast to inhalation injury, it is unlikely that a participant would not know whether they had spent time in an ITU.

In HIC studies, ITU admission is reported to be a statistically significant risk for burn contractures (Goverman et al., 2017a) and is presumed to reflect prolonged immobility and bedrest. The situation in LMICs is different, as the availability of ITU is limited and patients requiring ITU often do not survive.

Within the Government healthcare system in Bangladesh, ITU was only available to participants in DMCH, therefore in this present study an ITU admission may indicate that the patient received specialist acute burn care, which could explain why it appears to be a protective factor with respect to contracture. One potential benefit of burns ITU in HICs is early engagement with physiotherapy. However, as the median time to first meeting a physiotherapist in this study was 48.5 days, and the median length of stay in ITU was 30 days, it seems unlikely that physiotherapy input during the ITU stay explains the less severe contractures.

In HIC literature, need for skin grafting is often considered an indicator of a deep burn, which is itself a risk factor for contracture. Grafted wounds (and higher TBSA of grafts) have been shown to be independent risk factors for contracture formation (Gangemi et al., 2008; Goverman et al., 2017a and b; Kraemer et al., 1988; Schneider et al., 2006; Schouten et al., 2019) although grafting is intended to reduce scarring and therefore contracture. In HIC settings, if grafting is not necessary, the wound will often heal within a short time without scarring and not result in persistent contracture (Schouten et al., 2019), so rather than grafting being a risk factor itself, it is more likely only an indicator of severe injury.

In contrast, LMIC literature and the clinician interviews report lack of skin grafting rather than grafting as a risk factor for burn contracture formation. This study and other LMIC papers demonstrate, grafting may not be available for the majority in low-resource environments. A literature review examining studies describing burn care capacity across 14 LMICs reported that only 35.6% of hospitals could perform skin grafting and 37.9% contracture release (Gupta et al., 2014). This lack of grafting capacity is one of several significant differences in the standards of care (and probably also outcomes) between

HICs and LMICs. In the study by Puri et al. (2019), only 151/486 (31%) patients requiring subsequent reconstruction had undergone skin grafting during acute care, and only 12/151 were grafted within the first 3 weeks of burn.

In this present study, there was very little difference in contracture severity at person level for those who had been grafted and those who had not, which was unexpected. However, refusing a skin graft was a significant risk for contracture as described above.

At joint level, (perhaps a more appropriate unit of analysis for examining grafting as a risk factor), therapeutic interventions were initiated late and for shorter than normal durations. Although grafting did not significantly affect whether a joint became contracted or not, it did statistically significantly reduce the severity of contracture. Joints which were grafted were also statistically significantly more likely to have received pressure and positioning treatment. This probably reflects the increased availability of these adjunct specialist treatments in the centres providing grafting. Positioning did not appear to have any independent impact on contracture presence or severity in grafted joints, whereas pressure did, but it is not clear to what degree each of these risk factors impacted on contracture severity. Given the low resource environment, the more frequent use of pressure (which is expensive) than positioning or splinting (both cheap) is surprising.

The observed beneficial effect of skin grafting, like other specialist interventions, may also be an indicator of overall specialist care rather than a direct impact of grafting. However, it is likely that successful grafting even in a non-specialist centre, would directly reduce contracture severity because it reduces hypertrophic scar formation.

Gangemi et al., (2008) suggested that the type of skin graft may also be important and found meshed graft to be a statistically significant risk factor for contracture; in this study there were only 2 non-meshed sheet grafts out of a total of 20 therefore it was not possible to analyse any differences between types of graft.

The timing of skin grafting may also be important in preventing contracture. Grafting tends to be done later in LMICs compared with HICs and may have less impact on outcome than if it was done earlier. Early grafting is standard practice in HIC (often within 48 hours), but the average time to first graft at joint level in this present study was 7.35 weeks. Even using a more conservative definition of early grafting, i.e., within 3 weeks of the injury (Puri et al., 2019), only 4 participants in this present study had 'early grafting'.

In environments where multiple risk factors are operating simultaneously (rather than the more standardised care provided in HIC settings), grafting may have less visible impact on preventing contracture. One of the study participants had most of her burn grafted early (2 weeks post-injury) but despite this developed a very severe contracture, probably because of other factors which affected her care such as uncontrolled pain, lack of therapy or joint movement, discharge against medical advice and no follow-up.

A higher overall number of surgical procedures during acute burn care has also been found to be a significant risk for contracture (Gangemi et al., 2008; Hop et al., 2014); in addition to skin grafts these procedures are likely to include debridement, escharotomy, and fasciotomy. In the present study, only skin grafting and escharotomy could be documented as surgical procedures; data on other operations which may have been performed during the acute stage were not available.

Length of stay is often used as a proxy for severity of injury and longer LOS has frequently been cited as a risk factor for contracture (Bailey et al., 2019; Fadeyibi et al., 2015). Longer length of acute hospital stay has also been found to be a statistically significant risk factor in HIC literature (Godleski et al., 2018; Schneider et al., 2006,). Recently, Lensing et al. (2020) found that the number of days of bedrest was a more significant risk factor than simple LOS.

In the present study, participants with severe contractures had the longest LOS (median 8.5 weeks); presumably this may be related to the severity of their original burn. The median LOS for the study population overall was 10 weeks, which is considerably longer than in HIC studies (normally around 3 weeks and a common measurement point for contracture). In a study completed on 66 discharged burn patients from DMCH, the LOS for burn injured adults was reported to be 36.9 days and for children 25.3 days (Bailey et al., 2019). LOS as a measurable risk factor for contracture in LMIC is confounded by the many factors which influence a patient's willingness to stay in hospital, including costs, distance from family and the very different experience of hospitalisation in LMICs compared to HICs (Zaman, 2005).

A summary of current knowledge on key Medical/Surgical Treatment risk factors is shown in Table 8-5 below.

Table 8-5: Summary of surgical/medical risk factors identified by source

Risk Factor	Source and Details		
Surgical/Medical Treatment Factors	Existing Literature	Clinician Interviews	Present Study
ITU stay	HIC: Longer ITU stay*	✓	NS unexpected finding: participants with ITU stay had less severe contractures and less movement loss (small numbers 13/48) NS expected finding: of participants who had ITU stay, those with the most severe contractures had the longest ITU LOS
Escharotomy	HIC	✗	Data too limited - only 3/48 had escharotomies
No of surgical procedures	HIC: Greater no. of surgical procedures*	✗	✗No data on debridement, only small numbers >1 skin graft
Skin grafting	HIC: Presence of a skin graft*/ high TBSA grafted*	✗	Person level: no pattern Joint level: SSG did not affect whether joint contracted, but did affect severity of contracture, grafted joints had less severe contractures*
Lack of skin grafting	HIC and LMIC	✓	Person level: no pattern Joint level: SSG did not affect whether joint contracted, but did affect severity of contracture, grafted joints had less severe contractures*
Delay in grafting	HIC and LMIC	✓	NS unexpected finding: at joint level, participants without contracture had longer time to first graft Only 2 participants had 'early grafting' within 3 weeks of injury
Refusal of skin graft	LMIC	✓	Participants who refused skin graft had more movement loss*
Graft type	HIC: Meshed skin graft*	✗	✗only 3 sheet grafts, all other grafts meshed

(* = statistically significant, NS=not significant, ✓= mentioned only, ✗= not examined)

Table 8-5: (continued)

Risk Factor	Source and Details		
	Existing Literature	Clinician Interviews	Present Study
Surgical/Medical Treatment Factors (cont.)			
Graft failure	☒	✓	☒ only 3 graft failures
High TBSA grafted	HIC: Higher TBSA grafted*	☒	☒Data not available
Lack of nutrition	☒	✓	☒Data not available
Lack of pain management	☒	✓	☒Data not available
Longer time from burn to reconstructive surgery	LMIC	✓	Joints that have been reconstructed not included
Poor dressings	☒	✓	☒Data not available
Length of stay	HIC: Longer length of stay*	☒	No pattern observed
Complicated hospital stay	HIC	☒	☒Data not available
Duration of bed rest	HIC/UMIC: Longer bed rest*	☒	Data on bed rest and immobilisation collected, but deemed not meaningful for analysis
Adherence to treatment	HIC and LMIC	✓	Data not directly available, 6 participants reported inability to comply with treatment as the reason they developed a contracture. Majority of therapy interventions deemed ineffective - participants unable to wear garment/splint/position or exercise due to pain/heat/itch

* = statistically significant, NS=not significant, ✓= mentioned only, ☒= not examined

8.6.5.2 Rehabilitative Treatment Factors

In the present study, any rehabilitative interventions documented cannot be attributed to the input of a professional physiotherapist, as they would be in HIC settings. In DMCH, doctors prescribe and advise on exercise and positioning rather than therapists. Doctors may also prescribe splints or pressure garments, which are provided by orthotists/technicians not therapists. There is no monitoring of the effectiveness of prescribed interventions, nor of patient adherence to them.

The level of therapy input described in the HIC and UMIC studies reported in Chapter 2 is not available in the environment of this study; only 5 part-time physiotherapists covered all in and outpatients. Only a minority of participants in this study saw a physiotherapist at any time, and first contact with a therapist was late (median 48.50 days). According to HIC standards, physiotherapy should be instigated on the first day of admission (Edgar, 2009). Furthermore, average therapy time and total number of sessions were much lower than is normal in HIC burns units. Only 9/48 participants received any physiotherapy after hospital discharge.

Although not statistically significant, participants who did receive physiotherapy had less severe contractures and less movement loss than those who did not. However, as physiotherapy was only received by participants who were treated in DMCH or specialist centres overseas, other benefits of specialist care could confound this observation. It is also possible that only patients with the most severe burns or contractures were referred for physiotherapy and therefore the potential benefits of physiotherapy in less severe cases have been masked. As with other healthcare treatments in LMIC settings like Bangladesh, the amount of physiotherapy input is often affected

by the patient's ability to meet the direct and indirect costs of returning for follow-up.

There was an observed but not statistically significant pattern that those who were seen later by physiotherapy and for less time had greater movement loss than those seen early or for longer. Participants who were seen more than 20 times by a physiotherapist all attended private outpatient physiotherapists, this small group of patients ($n=6$) had an extremely low median loss of movement (0.23%) compared with those who were seen only once by a physiotherapist (median loss 26.38%). This illustrates the importance of defining the details of any therapy input (such as time of initiation and level of input) in studies of risk factors or interventions, rather than simply stating whether a patient received physiotherapy.

Only four other LMIC studies have collected data on the physiotherapy received by patients presenting with contractures requiring release (Kim et al., 2012; Ringo & Chilonga, 2014; Saaiq et al., 2012; Puri et al., 2019). None of these studies provided any details of the type of physiotherapy or the time it was initiated, but overall levels of physiotherapy input in these studies were even lower than in the current study. Puri et al (2019) did differentiate between effective and non-effective physiotherapy, although no definitions were provided; of 90/486 patients who received physiotherapy only 20 were deemed to have had effective physiotherapy. In a study of 31 reconstructed patients in India (Kim et al., 2012) only one had received physiotherapy and in a study from Pakistan by Saaiq et al, (2012) none of the 213 patients had received physiotherapy. In contrast, the Tanzanian study by Ringo & Chilonga (2014) reported that 70% of 41 acute burn patients had received physiotherapy.

Overall, at both person and joint levels of analysis in this study, those who had a therapy intervention had less movement loss than those who did not.

However, splinting (at both person and joint level) seemed to be associated (although not statistically significantly) with greater movement loss, which was unexpected. The reasons for this observation are not clear; these participants may have had more severe burns initially or the splints inadvertently resulted in prolonged immobilisation of the joint. During the pilot study, some acute cases were observed in whom splints had been applied in the wrong position, so it is important to be able to assess the effectiveness of a treatment risk factor and not just whether the treatment was given or not. Participants who were deemed to have had effective splinting did have less movement loss (17.50% median loss) than those with ineffective splinting (24.78% median loss).

Only a minority of participants had effective interventions; these were difficult decisions to make retrospectively but were based on participants' descriptions of the interventions, the time at which the intervention started and finished, and whether they adhered to the instructions given (Appendix 24). In the study by Puri et al. (2019), only 28/68 splints and 12/32 pressure treatments were deemed effective (definitions of effectiveness were not given).

One of the study participants was a private patient who declined ongoing physiotherapy (she had one appointment post-discharge) and had no splinting or pressure therapy. Despite this lack of therapy and a full thickness burn into her axilla and trunk, she had an excellent outcome. This patient had access to immediate specialist care, positioning/movement advice and close monitoring from her doctor, received grafting on day nine and was from a high-status socioeconomic background. These other factors may have compensated for the lack of physiotherapy in this case but are an unlikely set of circumstances for most burn patients in Bangladesh.

The only therapy input which had a statistically significant impact on contracture reduction in this study was pressure therapy. At person level, participants who had been issued pressure garments had statistically significantly less movement loss (LMSp). Joints which had pressure applied were also statistically significantly less likely to develop contractures, although there was no statistically significant relationship between pressure and contracture severity.

It could be that pressure had a direct effect on contracture occurrence by controlling hypertrophic scarring, or it may be that receiving pressure is only an indicator of the presence of other beneficial factors such as good adherence to treatment, higher socioeconomic status (pressure garments need to be purchased and are expensive), ability to return for review (pressure garments require frequent re-assessment and necessitate more frequent follow-up) or specialist care (only specialist centres provide pressure treatment). The fact that pressure did not have a significant impact on severity of contracture at joint level may suggest that it is more likely an indicator of the presence of other mitigating factors, although there was little difference in monthly income between those who had pressure treatment (median 20,000 BDT/month) and those who did not (median 15,000 BDT).

Of the three LMIC papers which used statistical analyses to identify risk factors for contracture (Agbenorku, 2013; Forjuoh et al., 1996; Fatusi et al., 2006), none included physiotherapy or any therapy interventions as potential risk or protective factors. Therefore, although physiotherapy is considered by most burns clinicians to be vital in reducing burn contractures, evidence of its use or effectiveness in preventing contractures in LMICs is currently lacking.

As very few of the therapy interventions which were offered to participants in the present study were considered effective, it is not surprising that so few

seemed to have any significant impact on contracture outcomes. This does not imply that therapy is not useful, but rather highlights a need for further research along with more professional and standardised therapy input for burn patients in Bangladesh.

A summary of current knowledge on key Rehabilitative Treatment risk factors is shown in Table 8-6 below.

Table 8-6: Summary of rehabilitation risk factors identified by source

Risk factor	Source and Details		
Rehabilitation Factors	Existing Literature	Clinician Interviews	Present Study
Lack of physiotherapy	HIC and LMIC: Lack of physiotherapy	✓	NS pattern: those who had any physio had less severe contractures and less movement loss than those who had none
Delayed physiotherapy	HIC and LMIC: Delayed physiotherapy	✓	NS pattern: those with most severe contractures had longest times to first contact with physio (median time to first contact 48.5 days)
Duration of rehabilitation input	HIC: Lack of rehab time HIC: Low ratio of rehab to hospital days	☒	NS patterns: longest physio Rx times in those without contracture; those with more f/u visits had least severe contractures
Ineffective rehabilitation interventions	HIC&LMIC: Short duration of splint/positioning	✓	NS pattern: Participants / joints that had effective positioning/splint/pressure had less severe contractures, but very few had effective interventions
Poor adherence to rehabilitation treatment	HIC: Low adherence to rehab Rx* HIC&LMIC: Unable to engage with rehab interventions	✓	8/12 interventions ineffective due to inability of participant to adhere
Lack of positioning	HIC&LMIC	☒	NS pattern participants / joints that had positioning had less movement loss than participants/joints not positioned
Lack of exercise	HIC: Lack of exercise; prolonged immobilisation of joint	✓	NS pattern participants / joints that had exercise had less movement loss than participants/joints not exercised
Lack of splinting	HIC: Lack of splinting	✓	NS Unexpected finding - splinted participants and joints had greater movement loss
Lack of pressure therapy	HIC/LMIC: Lack of pressure therapy	✓	Participants issued with pressure garments had less movement loss* Joints which had pressure less likely to develop a contracture*
Lack of scar massage / silicone gel	✓	✓	No pattern observed, very small numbers

* = statistically significant, NS=not significant, ✓= mentioned only, ☒= not examined

8.6.6 Healthcare System Risk Factors

A variety of healthcare system risk factors have been cited or claimed to be risk factors for contracture in LMICs. It is important to recognise that without exception, these have only been highlighted by LMIC authors or clinicians with LMIC experience. Such factors are not normally considered in HIC literature, because appropriate and timely healthcare access is expected. In LMICs, lack of or delay in accessing healthcare plays an important part in the outcomes of many conditions. Hendricks et al. (2021) showed that even in the catchment area of a large referral hospital in Tanzania, significant delays occurred in seeking treatment for acute burns or their sequelae.

In the present study, it was not possible to evaluate all potentially significant health system factors, including the numbers and distribution of health facilities, trained staff, available resources, or the overall quality of care. However, efforts were made to explore (directly or indirectly) some of the health system risk factors proposed in the literature and clinician interviews. These included time to treatment and the type/level of health facility utilised, reliance on traditional healers, delayed referral to specialist care, incomplete treatment, and duration of follow-up.

Others have suggested that delay in presentation to healthcare in burn patients is a risk factor for contracture (Biswas et al., 2020). It is also recognised that the use of traditional healers and other non-medical treatments is higher in LMIC settings, especially amongst the poor (Hendricks et al., 2021; Meng et al., 2020). Healthcare professionals interviewed at 3 district and 7 sub-district Government hospitals in Bangladesh reported that the two main challenges to the provision of burn care at district level were late presentation and reliance on traditional doctors (Biswas et al., 2020). The study by Biswas (2020) also

supported the observation in the present study that Government-provided burn care received by participants outside DMCH was often basic.

Although 5 participants in the present study did seek advice from village doctors or traditional healers as their first port of call, it was remarkable that, all but one participant attended a healthcare facility within 24 hours. Unfortunately, the study population cannot be considered representative of all burn patients in Bangladesh, but if this finding was confirmed in a larger study, it would suggest that awareness of the benefits of biomedical burn treatment is increasing in Bangladesh. However, it is more important to determine whether the first port of call was appropriate and/or led to a referral to a healthcare facility able to deliver effective burn care such as DMCH.

The most frequent site of first presentation was a District Hospital; this is appropriate but perhaps surprising, considering that many participants lived in rural areas where even District Hospitals are some distance away and the nearest healthcare access is often a government clinic with limited personnel and hours of operation. Conversely, it may be that the reason so many participants attended District Hospitals was because the nearest government clinic was closed at the time of their burn. Although a Burns Centre such as DMCH may be the best location for optimal burn care, it is not desirable that only one such centre should serve a country of almost 166 million inhabitants. This has been noted by others (Potokar et al., 2021) and burn care decentralisation is a strategy addressed by the MoH in Bangladesh.

It was also notable that most participants received definitive care in DMCH; this suggests that either some appropriate referral system is operating (albeit in the absence of any formal burn care network), or participants simply knew that DMCH was their best option. However, only 11/ 28 who received initial care in the specialist centre were treated there throughout.

Participants who had their definitive care in the specialist facilities of DMCH had more movement loss than those treated in other non-specialist centres, apart from those who had ‘no treatment’, who had the greatest loss. Rather than specialist care being a risk factor for contracture, this may be because the most severe burns (with the greatest contracture risk) were treated in the specialist centre. Participants who had specialist care had a median TBSA of 28.50% compared to a median TBSA of 17.50% in those who did not have specialist care. Although not statistically significant, movement loss was lower in those who had specialist care throughout (median loss 8.33% and only one severe contracture) than in those who did not (median loss 26.85%, and 11 severe contractures).

The quality and efficacy of acute burn treatment may have a greater impact on contracture outcome than any subsequent interventions. Further study would be required to explore this in LMIC contexts. At present, not receiving burn care in a specialist centre is the norm in many LMICs (Botman et al., 2021; Kim et al., 2012; Meng et al., 2020).

As yet, place of treatment and time to access care have not been evaluated as risk factors for contracture, although they were examined by Botman et al., (2021) in regard to barriers to timely surgical care for burn patients. It seems likely that in LMICs with limited specialist resources and long journey times to specialist centres for most of the population, such factors may be very important in determining outcomes.

Only two risk factors in the category of healthcare system factors were found to be statistically significant risks for contracture in this current study. The first was discharge against medical advice, which represents incomplete treatment. No HIC or LMIC sources cite this as a measured variable or risk factor, and it is unlikely to be a common occurrence in HIC settings. One study looking at

the economic impact of injury on 369 burns patients in primary and secondary care hospitals in Bangladesh found that 23% left before completing treatment; reasons for self-discharge were not given (Mashreky et al., 2008b).

In the present study, participants who were discharged against medical advice had statistically significantly more severe contractures and a statistically significant greater loss of movement, perhaps because treatment was truncated by patient/family choice and therefore optimal outcomes were not achieved. Discharge against medical advice, in a system where cost is directly related to LOS and basic costs are augmented by out-of-pocket fees (Zaman, 2005), is often due to poverty and inability to pay, rather than any opposition to suggested care. All participants who took discharge against medical advice reported lack of funds as their main reason, although the monthly incomes of those who self-discharged against medical advice (median 15,000 BDT) were similar to those of other participants (median 18,000 BDT).

During the present study, it was observed (from other participants and from the medical team) that there was some stigma against patients who had taken discharge against medical advice; they were not encouraged to return, and if they did, they were scolded for their decision. This likely means that those who took discharge against medical advice would also be reluctant to attend for follow-up and would only do so with a severe problem.

The second statistically significant risk factor in the healthcare access category was low number of follow-up visits, which is not discussed in any HIC or LMIC literature; in HIC settings follow-up is normally available for as long as required. In this study, whether participants had any follow-up (i.e., at least one review, compared to none) had no influence on contracture severity, however the number of follow-up visits was significant. Participants with the most severe contractures had a median of only one follow up visit, whereas

participants with mild contractures had a median of 11 follow up visits. The frequency of follow-up could be expected to have a direct impact on the severity of contracture through the advice/treatment delivered at consultations. Reasons for low follow-up frequency may be related to socioeconomic status, income, gender, educational level, lack of desire for treatment or distance from DMCH. In HICs, some loss of patient follow-up is also expected (Celis et al., 2003; Kolmus et al., 2012; Gorga et al., 1996), but numbers 'lost to follow-up' are much lower in health systems where follow-up is actively offered, missing patients are recalled, and cost may be less of an issue. In patient-driven follow-up systems such as that in Bangladesh, it is almost impossible to expect optimal outcomes, as problems are not discovered early enough (or at all) and therapeutic interventions cannot be offered in a timely fashion, even if available.

There is little doubt that many of the challenges facing Bangladeshi patients and clinicians in achieving optimal outcomes after burns are system related. A summary of current knowledge of key health system risk factors is shown in Table 8-7 below.

Table 8-7: Summary of healthcare system risk factors identified by source

Risk Factor	Source and Details		
Healthcare System Factors	Existing Literature	Clinician Interviews	Present Study
Lack of healthcare facilities	LMIC	✓	☒ Healthcare facilities not mapped or examined
Distribution of healthcare facilities	LMIC: Geography or distance limiting access to care	✓	NS Pattern: contracture severity and movement loss increased with time and distance from DMCH in Dhaka
Lack of healthcare facility utilisation	LMIC: Failure to access treatment *	✓	Unexpected NS finding - no remarkable difference in contracture severity or movement for participants who did or did not receive treatment in formal healthcare system (small number no treatment group, n=7/48)
Reliance on traditional healers	LMIC	✓	Only 4 used traditional healer
Place of initial treatment and level of health facility accessed	LMIC: Treatment in lower levels of healthcare*	☒	NS Pattern: those with first admission to a specialist burn centre had less severe contractures and less movement loss
Treatment in rural healthcare	LMIC: Treatment in lower levels of healthcare*	☒	NS Pattern: those with initial presentation to specialist centres had less severe contracture and less movement loss than those treated in non-specialist centres
Time from injury to hospital care	LMIC: Delayed presentation	✓	Unable to analyse as risk factor due to small numbers, only 1 participant who had hospital admission presented >24 hours post injury

* = statistically significant, NS=not significant, ✓= mentioned only, ☒= not examined

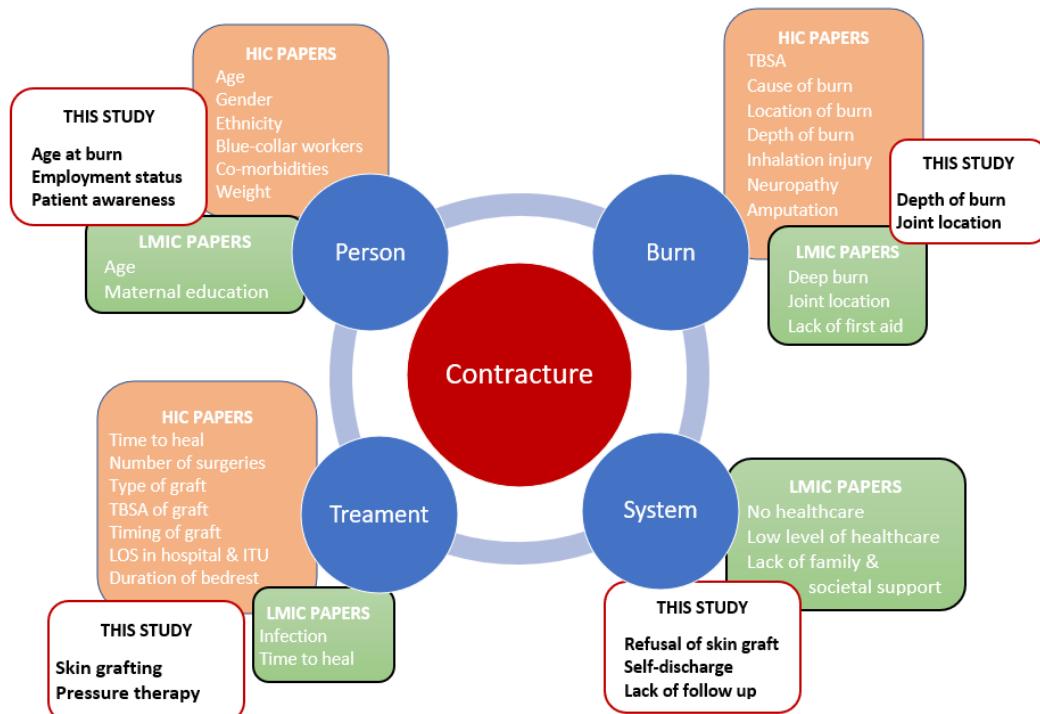
Table 8-7: (continued)

Risk Factor	Source and Details		
Healthcare System Factors	Existing Literature	Clinician Interviews	Present Study
Lack of trained staff	LMIC	✓	☒
Lack of resources	☒	✓	☒
Lack of MDT burn team	☒	✓	☒
Poor attitude of healthcare workers	☒	✓	☒
Focus on saving life rather than quality of life/good outcomes	☒	✓	☒
Lack of quality care	☒	✓	☒
Poor referral system / delayed referral to specialist care	LMIC: Delayed referral to specialist care	✓	Unable to examine – all participants who received specialist care were admitted on the day of the injury
Incomplete or ineffective treatment	LMIC: Incomplete initial burn care	✓	*Those who self-discharged early had more severe contractures and more movement loss
Lack of follow up	LMIC	✓	*Those with fewer follow-ups had more severe contractures and more movement loss NS Pattern: those who had any follow-up had less severe contractures and less movement loss cf those who had none

* = statistically significant, NS=not significant, ✓= mentioned only, ☒= not examined

A summary of the known statistically significant risk factors for contracture identified by this study from both HICs and LMICs is provided in Figure 8-2. The text box titled 'this study' refers to the statistically significant findings of the primary data. The central circles illustrate the proposed four main domains affecting contracture formation. In HICs, burn and treatment risk factors predominate, while in LMICs, health system issues are prominent; no health system issues have been identified in HICs. Refusal of skin graft and self-discharge is included in health system issues rather than treatment, as both result chiefly from patients' inability to pay for their care due to the system rather than the direct provision or lack of treatment.

Figure 8-2: Statistically significant risk factors for contracture in HICs and LMICs



8.6.7 Interactions between risk factors

It is likely that the risk factors for contractures are multiple, interconnected, and cross different categories of risk. Individual histories of the study participants exemplified some of these interactions; for example, lack of skin grafting was determined to varying degrees by participant reluctance and/or low socioeconomic status rather than simply by availability of grafting. Access to appropriate healthcare may also be affected by socioeconomic status and levels of awareness and may have a considerable impact on outcome. Even with timely appropriate specialist care, including early skin grafting, the outcome may still be poor due to the influence of other factors such as poor pain control inhibiting movement, needs of other family members, early discharge against medical advice, lack of further surgery due to limited funds, and lack of physiotherapy.

The nature of the interconnections between factors and their relative potencies are not yet understood.

8.7 MODIFIABLE RISK FACTORS

The purpose of identifying risk factors for any outcome is to endeavour to eliminate them and thus improve the selected outcome. This study has clarified the state of current knowledge of contracture risk factors, especially in LMICs. Further work is required to understand the relative potency of the risk factors identified and how they interact in different circumstances. Considering the number of potential risk factors now identified and the likely complexity of their interactions, eliminating them all will not be easy.

Publications from both HIC and LMIC sources frequently state that burn contractures are preventable, despite the evident lack of knowledge or

understanding of the risk factors which this study has uncovered. Despite higher standards of care and greater resources in HICs, reported prevalence rates of contracture remain high; in fact, HIC studies often report higher contracture rates than do those from LMICs.

Many of the risk factors identified by different sources could be considered 'secondary' as they are derived from other 'primary' risk factors. For example, the need for skin grafting (whether offered or refused) is probably indicative of a deep burn which is not expected to heal successfully on its own. Failure to adhere to treatment, including self-discharge from hospital before treatment is completed, may be the result of financial insecurity, lack of awareness of risk, or both. Delay in accessing appropriate medical care for an acute burn may be the result of poverty, gender, distance, lack of awareness or all of these. Much work is needed to separate true primary risk factors from secondary consequences.

This thesis has also revealed the range of health system issues which can contribute to contracture risk in LMICs and reaffirms how socioeconomic factors also contribute to adverse clinical outcomes. While this serves only to underline the impact of the social determinants of health (Commission on Social Determinants of Health, 2008), unless some of the inequalities identified can be addressed, the prevalence and severity of contractures (and indeed of burns themselves) is unlikely to change.

Forjuoh et al. (1996) introduced the concept of manipulatable or modifiable risk factors for burn contracture. From the collated knowledge of risk factors for contracture (Tables 8-2 to 8-7), it is possible to select those risk factors which may be modifiable; a summary of potentially modifiable risk factors is shown in Table 8-8 below.

It is apparent that even modification, let alone elimination, of all these risks (including inequalities in the social determinants of health) will require action on many fronts, by public health authorities and governments as well as burn professionals. This is not something which can be achieved by clinicians in the burns community alone; wider government action is required. With so many competing priorities for LMIC governments, it will be necessary for the burns community to demonstrate not only the personal human tragedies which result from adverse burn sequelae, but the overwhelming and potentially preventable loss of national productivity and economic well-being, before any significant action may be anticipated.

Table 8-8: Potentially modifiable risk factors for contracture in LMICs

Category	Modifiable Risk Factors
Demographic factors	Age at time of burn (through childhood burn prevention strategies)
	Lack of family support
	Low socio-economic level
	Poverty
	Inability to pay for care
	Illiteracy
	Education level
	Maternal education level
Patient characteristics	Lack of autonomy for women
	Co-morbidities
	Psychiatric history
	Psychological problems
	Fear/anxiety
Burn factors	Lack of knowledge on burn injury, treatment & risks
	Cultural beliefs
	Mechanism of injury especially flame burns
Surgical/medical treatment factors	Lack of appropriate First Aid
	Delay to first admission
	Tension over wounds
	Infection
	Pain management
	Delayed wound healing/closure
	Poor dressings
	Duration of bed rest
	Low albumin or protein levels
	Poor nutrition
	Lack of or delay in grafting
	Graft failure
Rehabilitation therapy factors	Patient refusal of skin graft
	Prolonged time from burn to reconstructive surgery
	Adherence to treatment
	Lack of/delayed physiotherapy
Healthcare system factors	Ineffective rehabilitation
	Lack of specific interventions
	Poor adherence to rehabilitation treatment
	Lack of health facilities in rural areas
	Time from injury to hospital care
	Reliance on traditional healers
	Lack of healthcare utilisation
	Level of initial healthcare accessed

8.8 POTENTIAL USE OF CONTRACTURE AS A QUALITY INDICATOR

Observations from this study show that:

1. The risk factors identified are diverse and extend beyond biomedical factors. Burn contractures appear considerably affected by factors related to the social determinants of health, which impact both the individual and the access to and effectiveness of healthcare.
2. Despite this, many of the risk factors for burn contracture are modifiable and therefore could be mitigated through prevention strategies.
3. The modifiable risk factors could be viewed as variables affecting overall quality of a healthcare system. This includes accessibility, equity, effectiveness, timeliness, and responsiveness of care, as well as the nature of clinical care delivered.

Therefore, it could be appropriate to consider using burn contracture, both in terms of incidence and severity, as an indicator of the overall quality of care received by burn patients in different countries, regions, districts or hospitals. In this respect, overall quality includes the contributions of health and social systems, individual institutions and indeed the patients themselves.

Due to the impact of socioeconomic factors on the presence and severity of contracture, it would not be appropriate to view contracture solely as an indicator of the quality of clinical care delivered, but rather as an overall indicator of the broader quality of the health system within which all influencing risk factors operate.

Subject to agreement on the definition and measurement of contracture presence and severity (a task that should be achievable through consensus), there may be potential for a contracture to do what other indicators do, which is to signal issues within the system. Contracture incidence and severity after burns could act as a relatively simple measure of a highly complex system,

which would otherwise defy measurement, and therefore improvement in LMIC settings.

It may be argued that contracture is only a single outcome (which is only measurable in survivors) and therefore a very blunt instrument with which to monitor the quality of overall burn care. While this is true, the same could be said for other accepted quality indicators, such as infant mortality or Accident & Emergency waits. The purpose of such quality indicators is not to attribute blame to individuals, departments, or institutions, but simply to raise a flag that something has gone wrong somewhere in the system and highlight systems with potential for positive change. As stated by a clinician interviewed and reported in Chapter 4, “When a contracture has developed – someone has missed an opportunity”.

Some may argue that a quality indicator requires a gold standard. While that is true, perhaps the goal (however unachievable) for contracture incidence (at a defined time-point) anywhere should be zero – as it is for maternal and infant mortality. This gold standard for contracture has been proposed by others: “Therapists need a mantra and activity level, which indicates that we do not accept even one contracture” (Edgar, 2009, p.368).

There are well established criteria which must be met for any variable to qualify as a quality indicator. With further work, contracture could have the potential to meet these criteria. In positioning contracture as an indicator of quality, increased focus on the incidence and severity of contracture as an outcome could drive improvements in the quality of health systems overall and subsequently reduce not only contracture presence and severity but also the associated cost and suffering, especially in LMICs.

8.9 LIMITATIONS

This study had several limitations which should be considered when interpreting the findings. If risk factors for contracture in LMICs are to be further explored and clarified, then the limitations of this study should be understood and, as far as possible, avoided in future work.

8.9.1 Research Design

This was a retrospective observational cross-sectional study based mainly on data collected from participants at interview. Although it was believed that the participants were a good source of data, and the best available in the circumstances, reliance on participants for accurate data has limitations. Much of the data collected from participants could not be triangulated with medical documentation, although some data could be confirmed through researcher observation. Medical records were incomplete and for some participants non-existent. Future studies in such settings are likely to face similar challenges unless studies are set up prospectively and all necessary data are collected at the time of acute burn. This approach requires long-term planning and execution as well as continuous quality monitoring and sufficient human and financial resources.

The use of interpreters was necessary, but it would have been preferable for them to have had more experience in research and interviewing. The interpreters were all medically qualified, their familiarity with the hospital environment and medical care was helpful, however, they did not have previous experience or knowledge of burns and contractures. Interpreters had variable fluency in English, which often prolonged the duration of the interview and possibly limited understanding. Lack of consistency in interpreters (new interpreters rotated every three days) was also a challenge.

The risks of using untrained interpreters in healthcare interviews are well-described (Kasten et al, 2020) and include mistranslation, conveying of the interpreter's views rather than the patient's and failure to transmit all relevant information, all of which could distort results (Brinkman, 2015). Studies led by trained and/or native language speaking researchers could overcome this problem, highlighting the need for local leadership of research from LMICs.

Although the doctors responsible for interpretation in this study were not involved in the care of the participant, the presence of a doctor and a foreign visitor may have caused social desirability bias in the responses given (Brinkmann, 2015). However, this was not believed to have influence during this present study, as most of the questions were factual and about the participants injury rather than about their opinions. It is theoretically possible that participants could indicate treatment was given that had not been (or vice versa), but there was no indication of this during the study. Each treatment question required some discussion, and it was clear whether the treatment had occurred or not. The only area where the researcher was aware that her presence may have had influence on participant response was regarding the costs of care and participants' monthly incomes. It is possible that some participants felt that the researcher might contribute to their incurred costs and therefore under-reported income and/or inflated their costs. This does not detract from the impact of high costs of care in low-income populations.

8.9.2 Population

The size and nature of the study population was a significant limitation to the overall ambitions of this study. Although participants demonstrated a broad range of risk factors in each category, due to the small size and self-selection of the study population it is not possible to conclude that the findings of this study would be transferable to the wider burn population in Bangladesh. The

low participant numbers means that the few statistically significant risk factors identified, and even those not found to be statistically significant, must only be considered as initial indicators rather than definitive answers.

Despite initial expectations, it proved difficult to include patients who were still in the acute phase of injury. This was largely due to the very different hospital and ward environments in Bangladesh, even in a specialist centre such as DMCH, compared with those of similar institutions in HICs. Consequently, the present study was limited to participants who were at varying points in the post-acute journey. This itself would not have been such a problem were it not for additional limitations on participant recruitment.

Due to the follow-up system in Bangladesh, patients who were available for inclusion in this study were a very self-selected group, probably representing only the highly motivated tip of an iceberg, in terms of all those with contractures. The lack of any meaningful denominators (total numbers of participants with at-risk joints or contractures) was also a limitation.

The obstacles faced by patients in attending follow-up also means that only those with significant problems are likely to attend. Consequently, very few participants without contractures were available for inclusion during the period of the study, making it difficult to evaluate the effect of risk factors on contracture occurrence at person level. To get a clear picture of the prevalence and potential risk of contracture, a prospective study of acute burn patients would be required, and incentives would likely to be required to encourage participants to return for assessment at an appropriate time after discharge.

Recruitment to the final study was also limited by the duration of the visa issued to the researcher (one month) and the inability to return for further data collection due to time, costs and COVID19.

8.9.3 Risk Factors Examined

The initial source of risk factors to be explored was the literature review. A potential limitation of the review was that studies focused on single non-major joints only were not included in the final study. It is possible that published studies of non-major joints could have yielded further information on potential risk factors for contractures. Additionally, all languages were not included in the literature review, thus excluding potential sources from non-English speaking LMICs. Despite these limitations, the literature review included a broader range and greater numbers of articles than any other investigations of risk factors for burn contracture to date and produced a large number of factors for evaluation. Although the literature review was comprehensive, and papers were critiqued in detail, no formal quality assessment tools were used to determine the internal validity of the various types of studies. Furthermore, as a sole researcher no other researcher was available to appraise the researcher's decisions on the identification of risk factors from the literature. Decision validation would only have been possible with a larger research team.

Following the pilot, consideration was given to reducing the number of risk factors for examination in the final study, but it was felt that any inclusions would have been subjective, with too little available data from LMICs to guide the process. It was deemed more appropriate to keep the frame of possible risk factors broad and conduct an exploratory/foundational study before focusing too narrowly.

Despite the diverse range of risk factors included in the DCT, there were many other potentially important factors that could not be investigated within the scope of the present study. These included biological features such as the genetics of individuals and their tendency to scar, broader health system

characteristics such as human resources and the number, type and training of healthcare providers delivering burn care. Even some factors included in the DCT were found to be unexaminable because reliable data were not available either from participants or medical records. Electrical burns were excluded from this study but are known to result in deep tissue damage with a likely greater contracture risk; an electrical burn may itself be a risk factor.

In some cases, the data obtained from participants should be regarded with caution. The unreliability of participant recall (especially without medical documentation) means that even basic burn details such as extent and depth of burn may be inaccurate. This may be why so many burn risk factors were not found to be statistically significantly associated with contracture presence or severity in this study.

The difficulty of determining whether an intervention was effective or not was also a challenge and limited determination of the importance of the intervention in reducing contracture. Ineffective interventions are often as inefficient as, or occasionally worse than, no intervention at all.

In other cases, potential risk factors were so widespread in the study population (e.g., poverty and lack of effective rehabilitation interventions), that no differences could be identified between different outcome groups.

It is normally considered preferable to separate examination of risk factors in adults from those in children, because of the potential effects of growth on contracture outcomes. In this study, although only adult participants were included, the initial intention to include only those who had sustained their burns as adults had to be adjusted due to the lack of eligible participants. Although no statistically significant difference was found between participants who sustained their burn in childhood vs adulthood in this study,

it is possible that with greater numbers more differences could have been observed. Due to the frequency of burns in children in LMICs, it is likely that recruitment to studies including childhood burns would be easier; experience in both the pilot and final studies suggested that had children been included in the study, participant numbers would have been considerably greater in both inpatient and outpatient groups. The pilot study showed that parents were an excellent source of information about their child's burn history and management, even several years after injury.

Due to the study design and unplanned nature of patient follow-up attendance, it was not possible to standardise the post-burn time of data collection and contracture measurement. The initial intention to include only participants who were >2 years but <10 years from injury, (to capture fixed contractures and reduce the impact of recall bias), had to be adjusted due to limited participant numbers. Although the median time post-burn was 2.5 years, the range was wide (7 months to 37.5 years). More than one third of participants had been burned <2 years previously; their contractures were likely still maturing and could still have improved or worsened, therefore the impact of some risk factors may have been over- or underestimated.

Lastly, there is evidence from previous literature and the findings of this study that the anatomical location of the joint is itself a risk factor for contracture, which is a confounding factor in all previous studies which include different joints in analyses of risk factors. There were insufficient numbers of participants and joints in the present study to stratify risk factor analyses by each anatomical joint location.

8.9.4 Outcomes

The main outcomes in this study were the presence and severity of contracture at major joints. Although they did not have a contracture of any included

major joint, 5 of the 9 included participants classified as having 'no contracture' at person level had a contracture of another joint or feature. This could have distorted the analyses of risk factors at person level; with hindsight, these patients should have been excluded from person level analysis.

As previously described and consistent with other studies, not every plane of movement at every included joint was measured. Furthermore, to save time FROM measurements were not consistently documented in degrees but rather assigned FROM on the data sheet. It would have been more exact to measure full ROM in all planes of movement at every joint. Those measurements taken to confirm full ROM gave rise to the observation that the study population had some ranges of movement that were greater than the normal reference full ROM used. This highlights the need for comparative reference ranges to be specific to the population being examined, as discussed previously.

One very important factor is the correct identification of a joint at risk of contracture. In this study, the definition of a joint at risk was stated and followed. However, as this was a retrospective study, without documented details of the initial acute burn (even documented TBSA was usually missing, let alone affected CFU determination), determination of a likely joint at risk was based on the researcher's clinical opinion of visible residual scarring. It is recognised that opinion on what would be considered 'enough' scarring on any part of a joint is subjective and likely to vary between clinicians; having more than one observer might have reduced potential errors.

8.9.5 Level of Data Analysis

The original aim was to include more sophisticated statistical analyses such as logistic regression and odds ratios to explore the relative importance of those

factors which were found to be statistically significant. Given the small sample size, the quality of the data (i.e., based on retrospective personal reports) and the amount of missing information, this was not possible.

8.9.6 General Challenges of Research in a LMIC Hospital Environment

In addition to the specific limitations described above, some general but important constraints were experienced during the investigation, which may also affect other clinical researchers in LMIC settings.

It is difficult for those without direct personal experience of working in LMIC healthcare systems to appreciate the enormous differences between these environments and what is usual in HICs. Furthermore, every LMIC is different; practices are influenced by cultural, religious and traditional beliefs. For those unfamiliar with Bangladesh healthcare, the description provided by Zaman in his ethnography of an orthopaedic ward in a Bangladesh teaching hospital is illuminating (Zaman, 2005).

It is important to take account of these differences in healthcare provision in any comparisons of LMIC and HIC data; the sheer numbers of seriously ill or injured patients being encountered daily by the often under-valued and underpaid staff in Bangladesh hospitals is overwhelming. Doctors and managers are focussed entirely on running a system which allows the maximum number of patients to be seen in the available time. Government health staff are not paid enough to dedicate all their time to Government hospitals, and many will depart for their private practices after lunch, leaving patients relatively unsupervised. Additionally, cultural norms especially those around the sanctity of women's roles within their own families, means that nursing as a profession does not attract the same respect or status, let alone remuneration (Hadley et al, 2007). It is not hard to see why nurses may be less motivated in that setting than in western HICs. All this creates major

challenges for rigorous and controlled clinical research in such settings, as was found during this study.

Due to the language barrier, lack of familiarity with the research process amongst hospital management personnel and the extremely high workload of key doctors and managers onsite, it was not possible to accomplish any logistic planning prior to the pilot and final studies. This made the pilot study even more important for identifying problems and becoming familiar with the environment and team; despite these efforts, the final study also required time onsite to overcome logistical challenges and gain local ethical approval. It may not be possible to improve this situation, even with greater pre-departure communication, but the kind of study that can be achieved is limited if the lead researcher is not in-situ. This is another pointer to the need for native and resident LMIC researchers to lead future investigations, as has been expressed by others (Franzen et al, 2017).

The environment for data collection for acute burns was difficult, as previously described, in terms of space, noise, overcrowding and lack of privacy. For outpatients, although some of these issues were less of a problem, there were a greater number of time pressures. Any interviews needed to avoid the participant missing seeing their doctor or being delayed in returning home. As the mean participant single journey travel time was 4 hours, unnecessarily delays to participants was important. Furthermore, the outpatient clinic was only open from 8-2pm and so all interviews had to be completed in this period. The local hosts were not keen for the researcher to be in the hospital once key doctors had left for security reasons, which limited the research time each day.

The lack of electronic or other records for patients in LMIC hospitals is a drawback to rapid identification of eligible participants and estimation of

available numbers. Patient identification and recruitment in similar settings cannot rely on planned admissions or outpatient appointments. The lack of detailed medical documentation also affects the ease with which data can be verified, especially in retrospective studies where current staff have little information to augment what is provided by the patients themselves.

There was limited local experience in, or capacity for, research in the study site; this has also been reported by others (Beran et al., 2017). In this study the limited research experience particularly affected recruitment and consent processes. Tsoka-Gwegweni and Wassenaar (2014) found informed consent and unbiased participant selection to be two of the most frequent ethical challenges related to research in LMICs. The basic training given to each new set of interpreters in the present study aimed to reinforce the importance of the informed consent process on the final outcomes/results, but some compromises were required between the ethical standards of UK universities and what was appropriate, or considered ethical, in this very different study environment. For example, provision of written participant information and time between recruitment and participation recommended by UK standards was impossible. Bitter et al (2020) also stressed the importance of considering local norms in securing informed consent.

The environment was also challenging at a personal level for the researcher. A study exploring ethical issues encountered by research staff during data collection in LMICs detailed the conflict between “feeling empathy for fellow human beings and exhibiting the level of detachment appropriate in their positions of research” (Steinert et al., 2021, p.4) and noted that when data is being collected in deprived areas, participants may seek financial or other help from the researcher. In addition, Steinert et al. (2021) stated “while research participants invest their time to take part in the study and disclose detailed

information during interviews, researchers may feel unable to substantially improve participants' lives...and the difficulty of researchers feeling unable 'to give something back' evoking feelings of guilt and helplessness" (p.4). This researcher could identify fully with each of these findings.

Despite the above, there are many advantages in conducting research in LMIC settings like Bangladesh; the numbers of patients with almost every clinical condition are enormous compared with HIC workloads, and opportunities for learning are correspondingly extensive. Burns and contractures are a huge problem in this environment and would benefit from greater investigation. Many presumed risk factors which are already controlled for in standardised HIC healthcare still influence outcomes in LMICs (e.g., late, or absent grafting, splinting and positioning), providing an opportunity for more detailed study.

However, without local leadership, even in conjunction with support from HIC research teams, the challenges presented to external researchers are unlikely to change and acquisition of locally relevant knowledge is unlikely to be acquired. 'Outsiders' may be viewed with caution (Zaman, 2015), (perhaps because of a tendency to make adverse comparisons with their own healthcare systems or unfounded judgements based on not understanding the local situation) and there is often reluctance to allow foreigners to undertake research in LMIC settings. It is extremely unlikely that the present study, with all its limitations, would have been permitted without the longstanding relationship between the researcher and the Burns Unit staff at DCMH. This relationship might be considered to have biased the study, but this was not apparent; the hospital team supported the research and allowed it to take place unhindered.

8.10 KEY CONTRIBUTIONS

Despite the limitations described, this work has advanced knowledge of risk factors for burn contracture in several ways. The literature review in this study is believed to be the most comprehensive review of potential contracture risk factors to date. Existing systematic reviews on burn contractures risk factors include considerably fewer papers possibly due to their strict inclusion criteria. All reported contracture risk factors (whether emanating from HIC or LMIC papers and whether putative or evidence based) have been collated with those from the present study in a categorised framework (Tables 8-2 to 8-7). These tables represent the most comprehensive summary of current knowledge and information on risk factors for contracture which is available at the time of writing. The range of risk factors identified gives an opportunity to look realistically at which of these can be explored in the LMIC context. It also identifies a battery of other factors for which further investigation is required, such as pain management and adherence to recommended treatments. Operationalisation of risk factors for investigation also requires further consensus and study.

As far as can be determined from the literature, this is the first study in either LMIC or HIC settings to take a holistic approach to potential risk factors for contracture by analysing them at both whole person and joint level.

At the time of conception, this was the first study from a LMIC to utilise a clear definition of contracture and outcome measures specifically designed for evaluation of whole-person risk factors as well as joint-specific factors. Both BCSCp and LMSp are new whole-person severity outcomes which have not previously been used in this way although both measurements are based on existing methods. LMSp also considers the number of joints at risk, using the risk-adjusted loss of movement outcome. While some may argue this is not

relevant to risk factors affecting individual joints, from the whole patient perspective it may be very important, especially when trying to evaluate system-based risk factors.

This is also thought to be the first study in which patients' perceptions of risk factors for their contractures have been considered. While these could have been investigated with more rigour, they are nevertheless important in understanding patients' perceptions of their problems and why they have occurred, which in turn can inform future study and interventions.

It is also the first study where the perceptions of clinicians with LMIC experience have been formally evaluated and reported. Although the factors identified as 'putative' in the literature review also represent clinical opinion, the present study specifically addressed, analysed, and incorporated clinicians' views on risk factors in the final study.

The DCT which was developed in this study is unique and could be made available for others to develop and use further. Future studies may also be facilitated by the ODK template which was created in this study, as this is now a ready-made and convenient data-input platform. Both the DCT and ODK platform would benefit from external peer review and testing.

Another key contribution is the recognition that joint location may have confounded the findings of previous risk factor studies. Future studies should evaluate risk factors at single joint locations. Furthermore, because of the interplay between different risk factors, much greater efforts should be made to control for burn variables such as depth, extent, and location, when evaluating the impacts of different treatments. Joint-specific factors such as grafting or splinting may be best examined using joint-specific outcomes;

conversely, evaluation of whole person risk factors require better whole person outcomes than are currently available.

This study has also uncovered the current lack of focus given to the definition of a joint in risk. Without a standardised definition of a joint at risk of contracture, studies on risk factors are likely to produce conflicting results, as is already evident from the literature. Varying definitions of joints at risk are likely to over or underestimate contracture prevalence and confound the identification of risk factors.

Of the risk factors identified, several are potentially modifiable. Some may be modified at clinical level, but others require action at government and public health level, which is challenging.

One notable factor which was found to be a risk for contracture in this study was participant awareness. Conveying appropriate and meaningful information on possible sequelae of injury is an important aspect of medical practice, costs little, and must be the responsibility of the healthcare community. This finding should encourage those in centres of excellence and the wider burns community to recognise their role in increasing patient and healthcare staff awareness of the risks and consequences of contracture in LMIC settings, a view supported by Puri et al. (2019). Encouraging and supporting patients to adhere to advice given, in order to prevent contracture development, is also important.

Lastly, the use of contracture as a quality indicator for the overall quality and effectiveness of burn care in a health system could help to focus attention on this poorly addressed but important and life-changing burn morbidity in LMICs.

9 RECOMMENDATIONS

9.1 RECOMMENDATIONS FOR FUTURE RESEARCH

This work has prepared the ground for future research into contracture risk factors which is badly needed. Due to the complexities of and differences between contracture risk factors in LMIC and HIC settings, it is recommended that future LMIC research in this area is led by clinicians, along with epidemiologists and public health experts, who work in LMIC settings, with support from research experts from HIC if needed. It is important that HIC advisors do not participate with expectations based on their own HIC healthcare experiences.

Further studies require larger study populations. Due to the high incidence of burns and lack of effective burn care, contractures are common in LMICs, therefore sufficient numbers should be available for study with appropriate planning and local leadership of the research.

With agreed standardisation of risk factor definitions and contracture outcomes, multicentre or national data collection could provide large amounts of data for analysis; institution of regional or national databases would greatly enhance knowledge and could also improve communications between specialist burn centre(s) and other hospitals.

In addition to individual studies, a Delphi process of burn care professionals could offer a very valuable resource for identifying and exploring risk factors for burn contracture. Patient perceptions of risk factors may also be relevant.

In the absence of formal patient follow-up/recall systems, some strategies will be needed to enable appropriate patient recruitment, especially for control groups of participants without contractures. Larger prospective studies may improve data collection, reduce participant loss and permit more advanced

statistical analyses, but will require sufficient duration to ensure contracture maturation and agreed time points for joint evaluation.

It will also be important to evaluate connections between risk factors and the relative potency of different risk factors; carefully matched control patients will be required to identify the impact of individual risk factors. Qualitative studies may reveal the reasons behind important risks such as discharge against medical advice or refusal of skin graft.

It will be important to develop improved, more standardised measures of contracture outcomes specifically for use in studies of risk factors. These must be applicable in the conditions faced in LMICs as well as HICs. Although the call for better definition and measure of contracture is widespread, different measures are required for different purposes.

There is an equally important need to agree what constitutes a joint at risk. Much more research is required to understand exactly how individual joint mobility is affected after a burn, and how local burn features, general patient attributes and the anatomy of the joint itself combine to put a joint at risk of contracture after burn injury. In the short term, clinical consensus could decide what constitutes a joint at risk of contracture; this definition could be applied for all future studies.

Although evaluation of contracture risk factors at both joint and person level is recommended, further work is required on how to accurately capture severity of contracture outcome at whole person level. Whole-person risk factors may best be examined using whole-person outcomes. Similarly, joint-specific risk factors may only be elucidated using joint-specific outcomes; because of the lack of homogeneity of risk at different anatomical joints, future studies need to control for inherent anatomical joint risk to avoid confounding the results.

It is recommended that future studies examining risk factors for burn contracture formation should include in planning and reporting the risk factor and outcome data listed in Table 9-1. This would improve the quality of risk factor and outcome data, enable more accurate identification of risk factors, and facilitate comparisons of studies. Currently, the majority of recommended reporting considerations are not included in publications, especially in LMICs studies.

Table 9-1: Key points for planning and reporting future risk factor studies

Risk Factor Data	Outcome Data
Outline the environment in which the study takes place and the standard care provided	State locations of joints included in the study, where possible evaluate different anatomical joints separately
State rationale for selection of the variables/risk factors being examined	Exclude previously reconstructed joints or present data separately
Provide definitions of risk factors and details of operationalisation	Provide definition used to determine a joint at risk
Describe characteristics of study population	Provide definition of contracture
Document time(s) when potential risk factors occurred (e.g., skin grafting, physiotherapy)	Document time(s) at which contracture outcomes are measured
Provide sufficient information on methods of data analysis	Provide method of assessment of contracture presence and severity
	Provide contracture measurement protocols (including movements, number of measurements, whether active or passive and normal reference ranges used)
	Provide the unit(s) of analysis (i.e., person and/or joint)

9.2 RECOMMENDATIONS FOR CLINICAL PRACTICE

This study revealed that there are some achievable changes which could be made to clinical burn care in Bangladesh (and perhaps other LMICs) which could begin the process of reducing contracture incidence and severity after burns. From the results of this study, including observations made during the pilot study and primary data collection, a limited number of suggestions have been generated for potential changes in clinical practice in DMCH/SHNIBPS.

It is evident that DMCH/SHNIBPS has developed a strong reputation and attracts patients from all over the country for both acute and reconstructive care. Despite significant resource limitations, DMCH/SHNIBPS provides burn care that can result in excellent outcomes. However, geography dictates that many patients are unable to reach DMCH/SHNIBPS. Many specialist aspects of burn care (such as burns ITU, skin grafting, reconstructive surgery, burns physiotherapy) were only readily available in DMCH/SHNIBPS.

Observations made on factors amenable to local modification and related suggestions for improvement are listed below in Table 9-2. The observations listed are based on direct observation during this study. The recommendations focus on potential areas for improvement, with recognition that financial and other resource constraints may preclude their full implementation. The suggestions build on the already substantial achievements of the staff of DMCH/SHNIBPS in promoting and providing the highest possible quality of burn care in Bangladesh. It is acknowledged that some of these recommendations may have already been tried, be in place or in the process of implementation.

Table 9-2: Observations and recommended solutions for clinical practice

<p><u>Observation 1</u></p> <p>Burn care in Bangladesh is very centralised and there is a lack of specialist care outside the capital</p>
<p><u>Recommendation 1</u></p> <p>Develop the capacity of burn specific specialised services and / or treatments in Medical College Hospitals within every Region of Bangladesh. Acute, follow up and reconstructive services could be offered. Capacity development could involve a telemedicine component if feasible</p>
<p><u>Observation 2</u></p> <p>The existing referral system appears to function informally but not all patients are able to follow the advice given and seek appropriate specialist care</p>
<p><u>Recommendation 2</u></p> <p>DMCH/SHNIBPS could provide electronic guidelines on continuing care and follow-up required after acute burns, (including recommendations for use of skin grafting, effective positioning, splinting, and exercise for joints at risk) which would be accessible by all surgeons treating burns in other District or Regional hospitals. Non-medical factors that are barriers to travel / admission could be explored and addressed. This is likely to require finance.</p>
<p><u>Observation 3</u></p> <p>There is a lack of documentation of key medical data even in DMCH/SHNIBPS, which if remedied could enhance patient care and future research</p>
<p><u>Recommendation 3</u></p> <p>DMCH/SHNIBPS could develop a core data set to be completed electronically or on paper for every burn admission, including all data deemed to be critical by DMCH/SHNIBPS staff for optimal care, monitoring of outcomes and future research. Similar core data sets could be created for patients attending DMCH/SHNIBPS after acute care discharge. The Global Burn Registry³ includes some but not all data required to monitor contracture risk. Appropriate medical, nursing or administrative staff could receive training on how to complete the datasets and encouraged to do so, despite the time required. This action could be the foundation for a regional or national database of patients with contracture</p>

³ <https://www.who.int/teams/social-determinants-of-health/safety-and-mobility/burns/global-burn-registry>

Table 9-2: (continued)

<u>Observation 4</u>
Many participants complained about high levels of pain which adversely affected their adherence to treatment and ability to move
<u>Recommendation 4</u>
Staff could be encouraged to implement existing pain control protocols, prescribe accordingly and monitor response
<u>Observation 5</u>
Patients who required specialised treatments such as skin grafts and physiotherapy, did not receive them in a timely manner, or at all. Time to first physiotherapy and time to wound healing was long
<u>Recommendation 5</u>
The recent skin graft protocol could be implemented consistently and audited to ensure all deep burns over joints are grafted early, especially for joints at high risk of contracture Physiotherapy could be initiated on admission for all patients at risk of contracture and continued after discharge as required
<u>Observation 6</u>
The multi-disciplined team (MDT) is very limited
<u>Recommendation 6</u>
The MDT could be expanded to include occupational therapists, psychologists, social workers and dieticians
<u>Observation 7</u>
There is little if any documentation of contracture presence or severity at any stage of care. DMCH/SHNIBPS is ideally placed to study contracture prevention and management. Currently there is no measurement system for contracture used routinely
<u>Recommendation 7</u>
DMCH/SHNIBPS could institute routine measurement of joints at risk on discharge and at subsequent follow-up. The method of measurement could be determined by DMCH/SHNIBPS staff but could be reproducible by different staff and feasible in the working environment. These measurements could be added to the core dataset described in Recommendation 3 above. This would enhance monitoring of patient outcomes, improve care, and provide a database for future research as desired by DMCH/SHNIBPS

Table 9-2: (continued)

<p><u>Observation 8</u></p> <p>The lack of any formal follow-up system means many patients are lost to follow-up and may never re-attend, or only when they have developed a severe complication</p>
<p><u>Recommendation 8</u></p> <p>In addition to verbal advice, DMCH/SHNIBPS could provide written, or audio/video recorded follow-up advice for patients on discharge (including self-discharges). This could include status on discharge, recommended action at home to prevent complications including contracture and recommended follow-up visits. This would improve patient care, perhaps improve outcomes and enhance available data for any future investigations they may wish to undertake. Cost alleviation for travel and follow-up treatment could increase return rates. A booking system for reconstructive surgery could increase patient motivation to return for follow up</p>
<p><u>Observation 9</u></p> <p>DMCH/SHNIBPS is ideally placed to lead research on identification and modification of relevant contracture risk factors in their own environment</p>
<p><u>Recommendation 9</u></p> <p>DMCH/SHNIBPS could consider the framework of risk factors presented in this thesis and select a number of most relevant risk factors on which to collect data at selected time points. Collaboration with other Medical College Hospitals in Bangladesh could increase availability of data for research led by DMCH/SHNIBPS</p>

10 CONCLUSION

The original research question posed was '**What are the risk factors for burn contracture formation in a low-income setting?**'. Although it has not been possible to answer the question fully, this work has contributed to greater knowledge of risk factors for contracture development in LMICs through consolidation of findings from previous studies of risk factors and other published literature, addition of new information on some LMIC risk factors not previously identified and creation of a categorised framework of potential risk factors for contracture in LMICs, which can now be explored further.

The framework developed illustrates the diversity of risk factors currently affecting contracture development after burns in LMICs. The overall conclusion must be that current knowledge and understanding of risk factors for contractures after burns in LMIC settings remains poor and incomplete.

Published HIC research on contracture development focus almost entirely on burn-related and biomedical factors, without consideration of the many other issues which affect LMICs. It is apparent that many of the risk factors for contracture which are currently ubiquitous in Bangladesh, and probably other LMICs, relate to socioeconomic and whole-system issues. Poverty is widespread and is an obstacle to accessing necessary healthcare and follow-up. Specialised burn care is very limited, centralised and no formal follow-up systems exist, making it impossible to ensure that patients with contractures are identified and treated in a timely manner. There also appears to be a lack of awareness in patients about the risk of contracture development and the associated high human and economic costs which can result. However, simply improving patient awareness will not overcome the many other barriers which are preventing good outcomes.

All these findings emphasise the need for a holistic approach in studies of contracture prevention. While HIC researchers may justifiably be interested in biomedical and treatment factors affecting their own burn populations, the wider burns community must support LMIC researchers and authors in determining the contracture risk factors most relevant in their environment and how to resolve or mitigate these risks.

This thesis has also demonstrated how differences in contracture definitions and measurement affect contracture incidence and severity, and thus the identification of risk factors. If we are to grasp the magnitude of the contracture problem in LMICs, a standardised, simple, objective, and reproducible method of evaluating contracture presence and severity must be agreed. The methods used in this study had some deficiencies but were for the most part objective, were shown to be feasible in a low-resource setting and could be reproducible by others.

This study has also uncovered that definition of joints at risk is almost absent in current literature, which also affects identification of risk factors. Variation in what is considered a joint at risk, in addition to a lack of standardisation of contracture measurement, may underlie the huge differences in reported contracture prevalence which are evident, even in HICs. The burns community needs to reach agreement on what constitutes a joint at risk, taking account of the factors that affect the level of risk at different joints.

The importance of determining a whole person outcome which takes account of the number of joints at risk is a new contribution; while not perfect, it serves to illustrate how results may be distorted if a single joint outcome is taken to represent the whole patient in cases where multiple joints are involved. There is a need for better and more accurate methods of expressing whole person outcomes, especially if whole person risk factors are to be examined

appropriately. Whether function or contracture is a better outcome depends on the purpose of the outcome evaluation. While function is important to patients and in clinical decision-making, for analyses of multiple risk factors, joint ROM may be a better outcome measure. This work has also highlighted that if joint ROM is used as an outcome for any purpose, there is a need for population-specific normal ROM ranges to be employed in calculating ROM deficiencies. This will require age, ethnicity and culturally matched reference values. Currently available methods of capturing contracture severity derive from HIC sources and do not accommodate the more severe contractures found in LMICs.

Also, because of the number of demographic (including socioeconomic), health system and other non-burn characteristics which appear to influence contracture development and severity in LMICs, future studies of individual surgical or rehabilitation treatment interventions in these settings should ensure that control groups are matched for non-treatment factors.

The thesis has presented some recommendations for future research which may be of value to other researchers in the field. Future researchers may find the challenges of research in the study environment described in section 9.5.6 useful to consider. The thesis also includes some direct observations and recommendations for improvements in some areas of current clinical practice in the study location. These recommendations may be helpful in the modification of risk factors, although it is recognised that resource limitations may preclude their uptake.

Burn patients in LMICs have very little voice to express their experience and needs. The lives of individuals and their families can be profoundly impacted by a burn injury, but they have very few options to combat the spiral of pain and poverty that can ensue other than to endure it. Clinical staff fight for

resources in a complex, overloaded and relatively 'chaotic' health service. Despite the evident need, policy change and service improvement are unlikely to occur without good quality data that reflects the reality of the situation. LMIC burn patients need the clinical and research burn communities to develop a more rigorous approach to measuring contracture risks and outcomes.

Individual participant stories which emerged during the field study illustrated the complex interactions between risk factors and showed how apparently similar burn and treatment factor risks may result in very different outcomes. The multifactorial nature of the risks and the broad canvas they inhabit means that their mitigation must involve all parts of the health system; successful change could result in a more equitable and effective system for all.

Burn prevention is inevitably focused on prevention of the original injury, but in a world where so many burn injuries result in debilitating contractures, more work is needed to understand the risks leading to contracture formation in order to reduce human suffering and increase the potential for a return to functionality and productivity. The day may come when there is international recognition of the importance of contracture incidence and severity as an indicator of the quality of the health system and burn care received, but until that time there is much work to do to fully understand the risks of burn contracture in LMIC settings.

APPENDICES

APPENDIX 1: CLINICAL INTERVIEW RECRUITMENT EMAIL

Subject Title: Expert opinion on the risk factors of burn contractures in LMICs

Dear XXXX

I hope this email finds you very well (plus a personalised greeting, opening comment if the participant is known to the researcher)

As a recognised global expert in burn care management, I would be extremely grateful if you would consider being a participant in our research study. This would involve a semi structured interview (approximately 45 minutes) by Skype, WhatsApp or Zoom (whichever is most suitable for you) at a time convenient to you. The interview will focus on risk factors for contracture formation in the context of low and middle-income countries. We are very interested in your opinion about which factors influence whether a patient develops a contracture or not.

Please find attached further detail on the purpose and process of the interview, and if you were able to participate a consent form to electronically sign and return.

(If not already known to the researcher) If you are able to participate, could you kindly let me know by email:

1. Your professional title
2. The health service type and geographical location – for example the village/town/city of xxx in the country of xxx and what level of healthcare your service is e.g. primary health care, secondary, tertiary or referral center.
3. Please do let me know what dates or times may suit you for the interview, ideally a date and time within the next two weeks if possible! If this is not possible, please let me know when you may be able to manage the interview.

Please do not hesitate to ask if you have any questions or require any further information. I am fully aware how extremely busy and in demand you are, please feel very free to decline this invitation if you are unable to participate, I will fully understand.

With many thanks, and I hope to see you xxx meeting (if appropriate and known to the researcher)

RuthAnn Fanstone

(Formal PhD / Swansea University Email Footer)

APPENDIX 2: PARTICIPANT INFORMATION SHEET FOR CLINICIANS

(on Swansea University Headed paper) Identification of Risk Factors in the Formation of Burn Contractures

As an expert in the area of burn care, you are being invited to take part in this research. Before you decide whether to participate, it is important for you to understand why the research is being conducted and what it will involve. Please read the following information carefully.

What is the purpose of the research?

The purpose of this research is to identify and explore the risk factors involved in the formation of burn contractures. The population of interest is adult burn patients in a low middle-income country context. You have been invited to participate because you are considered an expert in the field of burn care management and have experience working in a low and middle-income context. The research is important because effective prevention strategies for burn contracture formation are limited if risk factors have not been correctly and comprehensively identified.

Your participation in this study will take the form of a semi-structured interview by Skype or WhatsApp that will take approximately 45 minutes.

The risk factors that you identify will be used to develop a data collection form that we will use to examine patient care for the presence or absence of the various risk factors that literature and the expert group identify. At the end of the interview, you will be asked if you would be interested to review these data collection forms at a future date.

Who is carrying out the research?

The data is being collected by RuthAnn Fanstone, PhD student from the Global Centre for Burn Injuries Policy and Research (GCBIPR), Swansea University. The research has been approved by the College of Human and Health Sciences Research Ethics Committee.

What happens if I agree to take part?

Once you have read this information sheet, please ask RuthAnn if you have any further questions or require further information. Once you are happy with the purpose and process of participation, you will be asked to complete (with an electronic signature) and return by email the attached consent form. RuthAnn will liaise with you to find a convenient time to book the interview call with you. The interview can be made by WhatsApp, Zoom or Skype according to your preference. We would like to try to schedule the call with you within two weeks of your agreement to participate. Once an interview date is agreed, RuthAnn will send you by email one or two reminders about the upcoming interview time.

RuthAnn will conduct the interview from a private office within the Centre for Global Burn Injuries Policy and Research. The questions asked in the semi-structured interview guide a discussion with you on your overall experience in working with contractures (in brief), your opinion on what contracture is and how it may be measured. The focus of the interview is regarding your experience and opinion on the factors that determine whether a patient is likely to develop a contracture or not. You are encouraged to think as broadly on this topic as possible. You have been selected to participate because you are well known to have extensive experience in the field of burn care; no prior preparation for the interview is required! We are interested in your opinion and experience regarding burn contracture formation.

Within a week of your interview being completed, I will email you with the list of risk factors that you have identified so that you can confirm that I have heard you correctly. At this stage if you would like to add any further comments, these will also be incorporated. Individually you will not be linked with the risk factors you have identified.

Are there any risks associated with taking part?

The research has been approved by the College of Human and Health Sciences Research Ethics Committee. There are no significant risks associated with participation. If any issues around working with the challenges of burn contractures arise during our discussion, with your permission, we can bring them to the attention of the research team at GCBIPR for any signposting that may be possible.

If any of the issues raised in the interview caused you any concern, anxiety or distress please email my supervisors who have relevant experience to talk through any issues in full confidence. Professor Tom Potokar [REDACTED] is a burns and plastic surgeon and Professor Patricia Price [REDACTED] is a health psychologist, both with extensive experience in the field.

Data Protection and Confidentiality

Your data will be processed in accordance with the Data Protection Act 2018 and the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. The researcher/research team will only view your data.

All electronic data will be stored on a password-protected computer file on the researcher's encrypted laptop and on the personal desktop of the researcher in Swansea University. All paper records will be stored in a locked filing cabinet in the researcher's office at Swansea University. Your consent information will be kept separately from your responses to minimise risk in the event of a data breach.

Please note that the data we will collect for our study will be made anonymous from the start thus it will not be possible to identify and remove your data at a later date,

should you decide to withdraw from the study. Therefore, if at the end of this research you decide to have your data withdrawn, please let us know before you leave.

Conducting research overseas

The researchers will abide by local data protection laws when collecting personal data.

What will happen to the information I provide?

An analysis of the information will form part of our report at the end of the study and may be presented to interested parties and published in scientific journals and related media. Note that all information presented in any reports or publications will be anonymous and unidentifiable.

Is participation voluntary and what if I wish to later withdraw?

Your participation is entirely voluntary – you do not have to participate if you do not want to. If you decide to participate, but later wish to withdraw from the study, then you are free to withdraw at any time, without giving a reason and without penalty. The answers you provide for the interview will be incorporated into the next stage of the study within 48 hours of interview completion, after this stage it will not be possible to remove your responses from the study.

Data Protection Privacy Notice

The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data, and can be contacted at the Vice Chancellors Office.

Your personal data will be processed for the purposes outlined in this information sheet. Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you.

The legal basis that we will rely on to process your personal data will be processing is necessary for the performance of a task carried out in the public interest. This public interest justification is approved by the College of Human and Health Sciences Research Ethics Committee, Swansea University.

The legal basis that we will rely on to process special categories of data will be processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

How long will your information be held?

We will hold any personal data and special categories of data for ten years as stipulated by Swansea University.

What are your rights?

You have a right to access your personal information, to object to the processing of your personal information, to rectify, to erase, to restrict and to port your personal information. Please visit the University Data Protection webpages for further information in relation to your rights.

Any requests or objections should be made in writing to the University Data Protection Officer:-

University Compliance Officer (FOI/DP)

Vice-Chancellor's Office

Swansea University

Singleton Park

Swansea

SA2 8PP

Email : dataprotection@swansea.ac.uk

How to make a complaint

If you are unhappy with the way in which your personal data has been processed you may in the first instance contact the University Data Protection Officer using the contact details above.

If you remain dissatisfied then you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: -

Information Commissioner's Office,

Wycliffe House,

Water Lane,

Wilmslow,

Cheshire,

SK9 5AF

www.ico.org.uk

What if I have other questions?

If you have further questions about this study, please do not hesitate to contact us:

RuthAnn Fanstone

Global Centre for Burn Injuries

Policy and Research

Swansea University

Professor Tom Potokar

Global Centre for Burn Injuries Policy

and Research

Swansea University

E : [\[REDACTED\]](#)

APPENDIX 3: PARTICIPANT CONSENT FORM FOR CLINICIANS

(on Swansea University Headed paper)

Identification of the Risk Factors for Burn Contracture Formation

Principal Researcher – RuthAnn Fanstone, PhD Candidate, Global Centre for Burn Injuries Policy and Research, Swansea University, Swansea, SA2 8PP, Wales

	Participant initial
I (the participant) confirm that I have read and understand the information sheet for the above study (dated) which is attached to this form.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons.	
I understand what my role will be in this research, and all my questions have been answered to my satisfaction.	
I understand that I am free to ask any questions at any time before and during the study.	
I have been informed that the information I provide will be safeguarded.	
I am happy for the information I provide to be used (anonymously) in academic papers and other formal research outputs.	
I am willing for my information to be audio recorded.	
I have been provided with a copy of the Participant Information Sheet.	
I agree to the researchers processing my personal data in accordance with the aims of the study described in the Participant Information Sheet.	

Thank you for your participation in this study. Your help is very much appreciated.

Print name of participant

Signature

Date

Print name of researcher

Signature

Date

This study is being conducted by Swansea University, College of Human and Health Science.

When complete: Original copy for the participant, one copy to be retained by researcher

APPENDIX 4: GUIDE FOR INTERVIEWS WITH CLINICIANS

The interviewer will:

- ✓ Introduce themselves and thank the participant for agreeing to take part in the interview
- ✓ Go over the purpose of the interview and answer any questions the participant may have
- ✓ Discuss and agree use of the audio recorder or not
- ✓ Discuss confidentiality
- ✓ Advise the participant that they are free to terminate the interview at any time should they wish to do so
- ✓ Go through consent form

Demographic information related to profession, duration of relevant work experience, and place of work will be noted ahead of the interview.

Section 1: Introduction and purpose of study and interview

Section 2: Participant Information and relevant background

- Profession
- Place of work
- Type of work
- Adults or paediatrics or both
- Years in burn care
- Experience in low- and middle-income countries / high income countries or both
- Is the experience acute or reconstructive or both
- Where has the experience been – which countries, hospitals, environments
- How much experience with burn contractures – time
- Have you seen many contractures? Try to quantify
- Are contractures common in your unit?
- How severe are the contractures in your unit?

Section 3: Questions

Definition of a burn contracture

1. How would you define a burn contracture?
2. Can you explain how you would identify a contracture clinically?
3. Are you confident in being able to definitively diagnose a contracture clinically?
4. What approaches/criteria do you use to measure a contracture?
5. What challenges if any do you face in assessing contracture?
6. What challenges if any do you face in measuring a contracture?
7. Do you record any measures for contracture in your hospital management system (data collection)

Preventability?

8. Do you believe that burn contractures are preventable?

Prompts

- Tell me more
 - Are they preventable in all contexts? If not what contexts?
9. What if anything does a contracture tell you about a patient or their care?
 10. How competent do you feel to prevent and treat contractures?

Prompts

For example if you are on a ward round and you see a contracture has developed does it tell you something

If you were in outpatients and you saw a patient with a contracture, what would it tell you about the patient or their care?

Risk and Protective Factors

11. What do you think the risk and protective factors for contracture formation are? (explain / define risk and protective factor) Please think broadly as possible and brainstorm as many factors as you can think that are relevant.
12. Do you think our patients understand what a contracture is and how to prevent one?

Impact of time on a burn contracture formation

13. What would you say is the earliest time point that you would see a burn contracture starting to develop?
14. At what time point do you think a contracture becomes fixed (non-changeable with conservative management, requires surgical intervention)?
15. At what stage of the patient journey do you think that contractures most likely to develop?
16. Do you think that there is a stage of the patient journey when factors/intervention can most influence the final outcome of contracture?

Weighting of factors

17. In your opinion what are the most important or influential five risk factors?
18. Do you think there is anything that protects the patient from a contracture (that isn't also a risk factor)?
19. Do you think contractures are i) more common ii) more severe in low and middle-income countries? If so, why?

Source

20. Where does your knowledge on what factors influence contracture formation come from mainly? Could you put a % to it ... i.e., is 70% from experience and 30% from literature.

Prompt

- If they focus on literature ask them specifically what literature has influenced them

Final Questions

21. Do you have further comments on the topic? Anything else to say?
22. Could you look (listen) to my working definition of burn contracture for purposes of my study and do you have any comments / feedback on it?

For my study, I will need a working definition and measure of a burn contracture. A burn contracture is defined as any loss of movement of a joint due to restrictive scarring. For both reconstructive and acute patients, I will take three measurements on two movements (active and passive). The three measurements will be i) researcher 1 measuring with a goniometer, ii) researcher 2 measuring

with a goniometer and iii) measurement with a digital device. All measurements are made in degrees of movement of the contracted joint. Do you have any comments on this definition and measurement protocol?

APPENDIX 5: ETHICAL APPROVAL PHASE 1

From: [REDACTED]@Swansea.ac.uk> On Behalf Of CHHS Ethics
Sent: 10 April 2019 15:30
To: FANSTONE R. ([REDACTED])<[REDACTED]>; CHHS Ethics [REDACTED]@swansea.ac.uk>
Cc: [REDACTED]
Subject: RE: Ethics application - RuthAnn Fanstone Reference 200219b

Dear RuthAnn,

Many thanks for your e-mail.



Your draft debrief is fine. Again, if you can send me details when you have more information that is great. Again, this will not hold up approval of your study.

Approval for your study is now granted, subject to you sending me approval from the Ministry of Health in Bangladesh. **Can you please forward me this permission when received, as it is a condition of approval, and should be received before any research is undertaken.** I wish you well with your research.

Best wishes,



Angela Smith

Senior Lecturer in Health Care Law and Ethics | Uwch Ddarlithydd mewn Cyfraith Gofal Iechyd a Moeseg

Chair, CHHS Ethics Committee

<https://www.swansea.ac.uk/humanandhealthsciences/research-at-the-college-of-human-and-health/research-ethics-committee/>

APPENDIX 6: LIST OF RISK FACTORS FROM CLINICIAN INTERVIEWS

Risk Factor	Frequency of report
PERSON, NON-BURN FACTORS	
Biology of patient (genetics increase risk of scarring)	8
Lack of education	5
Low mood and psychological problems	4
Lack of intelligence	3
Presence of co-morbidities	2
Younger age	2
Lack of finance to pay for treatment	2
Lack of understanding on necessary treatment such as exercise	2
Lack of understanding re: burn injuries and treatment	1
Illiteracy	1
Learning difficulties	1
Psychiatric history	1
Lack of strength	1
PERSON, BURN FACTORS	
Lack of treatment adherence	9
Location of burn: hands and fingers (n=5), joints (n=1), eyes (n=1), upper limbs and neck (n=1)	8
Deep burns	7
Late presentation to treatment	3
High TBSA	2
Unwilling to agree to skin grafting	2
Lack of patient understanding of the seriousness of a burn injury	1
Tension over the healing area	1
Low albumin and protein levels	1
Lack of nutrition	1
Lack of personal hygiene	1
Belief that the burn patient will die	1
Poor pain tolerance	1
Nerve injury following electrical burn	1

Risk Factor	Frequency of report
TREATMENT	
Lack of splinting	10
Delayed treatment	6
Lack of physiotherapy	6
Lack of positioning	6
Lack of pain management	4
Lack of skin grafting	4
Delayed wound closure	4
Delayed skin grafting	3
Lack of exercise	3
Self-treatment	2
Lack of scar management	2
Ventilated patients	1
Delayed reconstructive surgery	1
Lack of treatment	1
Poor dressings	1
Lack of scar massage	1
Lack of mobilisation	1
Lack of pressure therapy	1
COMPLICATIONS	
Wound infection	7
Graft failure	1
FAMILY AND COMMUNITY	
Lack of intelligence	2
Unwilling to agree to skin grafting	2
Lack of education	2
Lack of understanding regarding the seriousness of a burn injury	1
Lack of personal hygiene	1
Lack of treatment adherence	1
Lack of awareness of treatment needed	1
Family belief that the burn patient will die	1
Lack of care and support from the family to the burn patient	1
HEALTHCARE CAPACITY	
Lack of trained staff	8
Lack of specialist burn care and facilities	5
Lack of adequate burn care	4
Lack of resources	4

Risk Factor	Frequency of report
HEALTHCARE CAPACITY (cont)	
Large number of burn patients and significant number of severe burns / Less energy in healthcare givers due to large volume of patients, many of these severe injuries	4
Lack of continuing care and follow up	3
Lack of multidisciplinary burn team	3
Poor referral system	2
Poor attitude of healthcare providers: Apathy / lack of initiative of staff	2
Lack of focus on outcomes of care / Focus on saving life, not quality of life	2
Staff believe burn patients will die	1
Lack of primary prevention	1
Need to pay for healthcare	1
Lack of facilities in healthcare facilities to encourage movement, no playroom	1
Burn care is unglamorous compared to plastic surgery	1
Conservative hospital protocols e.g., skin grafting not encouraged	1
Lack of access	1
Early discharge due to lack of patient finance	1
Lack of quality care	1
SOCIETAL AND ENVIRONMENTAL	
Low socioeconomic level	4
Lack of access to burn care due to geography and financial cost	2
Wealthy people will find the burn care that they need but this is not possible for the average burn patient	2
Lack of Government financial support	2
Lack of Government support for all aspects of healthcare	1
Lack of basic infrastructure such as electricity therefore more open fires and more burns	1
Lack of political commitment and support	1
Lack of appropriate first aid	1
Common occurrence of mass causalities	1
Reliance on traditional healers	1
Cultural beliefs (e.g., re: grafting) and religious beliefs (e.g., God will heal them without treatment, or the burn is due to sin)	1
Women are not able to make decisions for themselves	1

APPENDIX 7: ACUTE GROUP INTERVIEW GUIDE PILOT STUDY

4/5/2019

Acute_Patients_Form

Acute_Patients_Form

This form is split into 7 sections and aims to extract data from acute burn patients at a hospital in Bangladesh

Today's Date

yyyy-mm-dd

PATIENT DEMOGRAPHIC DATA

Patient number (patient's hospital number)

Study No (researchers identification system)

Age (notes, patient)

Gender (notes, researcher)

- Male
- Female
- Trans* male
- Trans* female
- Gender non-binary
- Self-Defined (please state)

Education at the time of the injury (patient)

- None
- Primary Incomplete
- Primary complete
- Secondary incomplete
- Secondary Complete
- Tertiary incomplete
- Tertiary Complete
- Adult education
- Other

If other education, fill in text box.

https://odk.enke.to/preview?form=https://xlsform.opendatakit.org/downloads/kib1kibe/Acute_Patients_Form.xml

1/27

Employment (patient)

- Unemployed
- Not paid/House work
- Self Employed
- Informal Employment
- Formal Employment
- Student
- Other

If other employment, fill in text box.

Income Level (patient, staff)

- No Income
- <£300 per year
- £300-£1000 per year
- £1000- £5000 per year
- >£5000 per year
- Other

If other income , fill in text box.

Rural/Urban (patient)

- Rural
- Urban
- Semi Urban

Ethnicity (Only ask if not Bangladeshi) (researcher)

- Bangladeshi
- Other

Ethnicity if not Bangladeshi

PATIENT OPINION

Does the patient have any contractures? (Observed by researcher- no measurement required)

- Yes
- No
- Don't know

If the patient DOES NOT have a contracture- has the patient heard of the term 'contracture (use Bangla word)'? (researcher asks patient)

- Yes
- No
- Don't know

If yes, what do you think it means? (researcher asks patient)

If the patient HAS a contracture ask " Do you have a name for this (point at contracture), the tightness that stops you fully moving your (name joint or body part)"? (researcher asks patient)

- Yes
- No
- Don't know

If yes, what do you call it? (researcher asks patient)

Why do you think you have a contracture (what has caused the contracture)? (researcher asks patient)

Can you identify anything that you think makes the contracture better (clarify better as appropriate e.g. less stiff) ? (researcher asks patient)

- Yes
- No
- Don't know

If yes, what makes it better? (researcher asks patient)

Can you identify anything that you think makes the contracture worse (clarify worse as appropriate e.g. more stiff)? (researcher asks patient)

- Yes
- No
- Don't know

If yes, what makes it worse? (researcher asks patient)

If the patient has a contracture, did they know that they may get one? (researcher asks patient)

- Yes
- No
- Don't know

HEALTH CARE SYSTEM : First Aid, Finance and Follow up

When the burn happened what did you do immediately? Prompts - did you remove your clothes, did you put anything on the burn, how long after the burn did you do these things, if you applied water how long for? (notes, researcher asks patient)

How many days (or weeks) was it between the time you got the burn injury and the time that you went for treatment? (notes, researcher asks patient)

- Same day
- Next day
- Within 5 days
- 5 days- 2 wks
- 2wks- 1 month
- 1month - 2months
- > 2 months
- Other

Additional notes on time between injury and treatment

Where (what person/place) was the first treatment? (notes, researcher asks patient)

- Traditional Medicine
- Friend
- Medical University,
- Medical College Hospitals
- Specialized Hospitals
- District Hospitals
- Mother and Child Welfare Centers
- Upazila (Sub District) Health Complex,
- Union Health & Family Welfare Centers,
- Community Clinics
- Non-Government Organization
- Private institutions
- Other

If other, where did they go first? (notes, researcher asks patient)**Was the first treatment appropriate? (researcher decides based on information given in comparison to evidence)**

- Yes
- No
- Don't know

How many days (or weeks) was it before you came to this hospital? (notes, researcher asks patient)

- Same day
- Next day
- Within 5 days
- 5 days- 2 wks
- 2wks- 1 month
- 1month - 2months
- > 2 months
- Other

Additional notes on time between injury and hospital admission**Why could you not come to this hospital more quickly? (Only ask if not on same day) (research asks patient)**

How did you travel to the hospital? (notes, researcher asks patient)

- Walking
- Bicycle
- Animal
- Motor Bike
- Three Wheelers
- Public Bus/Minivan
- Train
- Taxi
- Private Vehicle
- Ambulance
- Other

If other travel mode , fill in text box.

Distance of home from Dhaka (patient, researcher)

- < 1hour
- 1- 3 hours
- 3- 6 hours
- >6 hours

How far was the journey to the hospital in kilometres? (patient, researcher)**Do you have to pay for any aspects of your care here? (researcher asks patient and significant other, researcher asks staff)**

- Yes
- No
- Don't know

If yes, what do you have to pay for? (researcher asks patient and significant other, researcher asks staff)

- Operation
- Dressing Materials
- Dressing Procedure
- Pain Medication
- Antibiotics
- Other Medication
- Food
- Splints
- Therapist
- Other

If they had to pay for other aspect of care not on the list, what were they? (researcher asks patient and significant other)

Is there any treatment you have been told that you need but you have decided not to have because you don't have the money for it? (researcher asks patient and staff)

- Yes
- No
- Don't know

If yes, what treatment have you been told you need that you don't have money for? (researcher asks patient and staff)

- Operation
- Dressing Materials
- Dressing Procedure
- Pain Medication
- Antibiotics
- Other Medication
- Food
- Splints
- Therapist
- Other

If there are other treatments not listed in the categories that you were told you needed that you couldn't pay for, what were they exactly? (researcher asks patient and staff)

ABOUT THE BURN INJURY

Date of burn (notes and patient)

yyyy-mm-dd

Date of arrival in this hospital (notes and patient)

yyyy-mm-dd

What caused the burn injury? (select one from list) (notes and patient)

- Flame
- Hot Surface
- Hot liquid, steam or gas
- Electrical
- Chemical
- Friction
- Inhalation
- Cooling
- Radiation
- Other

Was the burn injury intentional? (notes and patient - patient is not asked directly - box is ticked only if in notes or offered by patient in history)

- Yes
- No
- Don't know

Total Body Surface Area of Burn (TBSA) (to the nearest full percentage)**Upload a picture of the chart (researcher)**

Click here to upload file. (< 5MB)

Associated smoke inhalation injury (notes, patient, researcher observation)

- Yes
- No
- Don't know

Was the burn injury on the neck? (notes, patient, staff, researcher observation)

- None
- Front
- Back
- 1 Side
- 2 Sides

If the burn was on the neck what was its depth? (notes, staff, researcher observation)

- Superficial
- Partial
- Full Thickness
- Mixed

Has the wound on the neck healed?

- Yes
- No
- Don't know

If it has, when did it heal? (notes, staff, researcher observation)

- >3 weeks
- 3-6 weeks
- >6weeks

Has the neck been grafted? (notes, staff, researcher observation)

- Yes
- No
- Failed

Is there a splint on the neck? (notes, patient, staff, researcher observation)

- Yes
- No
- Don't know

Was the burn injury on the right shoulder? (notes, patient, staff, researcher observation)

- None
- Top
- Dome
- Inner
- Outer

If the burn was on the right shoulder what was its depth? (notes, staff, researcher observation)

- Superficial
- Partial
- Full Thickness
- Mixed

Has the wound on the right shoulder healed? (notes, staff, researcher observation)

- Yes
- No
- Don't know

If it has, when did it heal? (notes, staff, researcher observation)

- >3 weeks
- 3-6 weeks
- >6weeks

Has the right shoulder been grafted? (notes, staff, researcher observation)

- Yes
- No
- Failed

Is there a splint on the right shoulder? (notes, patient, staff, researcher observation)

- Yes
- No
- Don't know

Was the burn injury on the left shoulder? (notes, patient, staff, researcher observation)

- None
- Top
- Dome
- Inner
- Outer

If the burn was on the left shoulder what was its depth? (notes, staff, researcher observation)

- Superficial
- Partial
- Full Thickness
- Mixed

Has the wound on the left shoulder healed? (notes, staff, researcher observation)

- Yes
- No
- Don't know

If it has, when did it heal? (notes, staff, researcher observation)

- >3 weeks
- 3-6 weeks
- >6weeks

Has the left shoulder been grafted? (notes, staff, researcher observation)

- Yes
- No
- Failed

Is there a splint on the left shoulder? (notes, patient, staff, researcher observation)

- Yes
- No
- Don't know

Was the burn injury on the right elbow? (notes, patient, staff, researcher observation)

- None
- anterior
- posterior
- inner
- outer

If the burn was on the right shoulder what was its depth? (notes, staff, researcher observation)

- Superficial
- Partial
- Full Thickness
- Mixed

Has the wound on the right elbow healed? (notes, staff, researcher observation)

- Yes
- No
- Don't know

If it has, when did it heal? (notes, staff, researcher observation)

- >3 weeks
- 3-6 weeks
- >6weeks

Has the right elbow been grafted? (notes, staff, researcher observation)

- Yes
- No
- Failed

Is there a splint on the right elbow? (notes, patient, staff, researcher observation)

- Yes
- No
- Don't know

Was the burn injury on the left elbow (notes, patient, staff, researcher observation)

- None
- anterior
- posterior
- inner
- outer

If the burn was on the left elbow what was its depth? (notes, staff, researcher observation)

- Superficial
- Partial
- Full Thickness
- Mixed

Has the wound on the left elbow healed? (notes, staff, researcher observation)

- Yes
- No
- Don't know

If it has, when did it heal? (notes, staff, researcher observation)

- >3 weeks
- 3-6 weeks
- >6weeks

Has the left elbow been grafted? (notes, staff, researcher observation)

- Yes
- No
- Failed

Is there a splint on the left elbow? (notes, patient, staff, researcher observation)

- Yes
- No
- Don't know

Was the burn injury on the right wrist? (notes, patient, staff, researcher observation)

- None
- anterior
- posterior
- Inner
- outer

If the burn was on the right wrist what was its depth? (notes, staff, researcher observation)

- Superficial
- Partial
- Full Thickness
- Mixed

Has the wound on the right wrist healed? (notes, staff, researcher observation)

- Yes
- No
- Don't know

If it has, when did it heal? (notes, staff, researcher observation)

- >3 weeks
- 3-6 weeks
- >6weeks

Has the right elbow been grafted? (notes, staff, researcher observation)

- Yes
- No
- Failed

Is there a splint on the right wrist? (notes, patient, staff, researcher observation)

- Yes
- No
- Don't know

Was the burn injury on the left wrist (notes, patient, staff, researcher observation)

- None
- anterior
- posterior
- Inner
- outer

If the burn was on the left wrist what was its depth? (notes, staff, researcher observation)

- Superficial
- Partial
- Full Thickness
- Mixed

Has the wound on the left wrist healed? (notes, staff, researcher observation)

- Yes
- No
- Don't know

If it has, when did it heal? (notes, staff, researcher observation)

- >3 weeks
- 3-6 weeks
- >6weeks

Has the left wrist been grafted? (notes, staff, researcher observation)

- Yes
- No
- Failed

Is there a splint on the left wrist? (notes, patient, staff, researcher observation)

- Yes
- No
- Don't know

Was the burn injury on right hip? (notes, patient, staff, researcher observation)

- None
- anterior
- posterior
- inner
- outer

If the burn was on the right hip what was its depth? (notes, staff, researcher observation)

- Superficial
- Partial
- Full Thickness
- Mixed

Has the wound on the right hip healed?

- Yes
- No
- Don't know

If it has, when did it heal?

- >3 weeks
- 3-6 weeks
- >6weeks

Has the right hip been grafted?

- Yes
- No
- Failed

Is there a splint on the right hip? (notes, patient, staff, researcher observation)

- Yes
- No
- Don't know

Was the burn injury on left hip? (notes, patient, staff, researcher observation)

- None
- anterior
- posterior
- inner
- outer

If the burn was on the left hip what was its depth? (notes, staff, researcher observation)

- Superficial
- Partial
- Full Thickness
- Mixed

Has the wound on the left hip healed? (notes, staff, researcher observation)

- Yes
- No
- Don't know

If it has, when did it heal? (notes, staff, researcher observation)

- >3 weeks
- 3-6 weeks
- >6weeks

Has the left hip been grafted? (notes, staff, researcher observation)

- Yes
- No
- Failed

Is there a splint on the left hip? (notes, patient, staff, researcher observation)

- Yes
- No
- Don't know

Was the burn injury on right knee? (notes, patient, staff, researcher observation)

- None
- anterior
- posterior
- inner
- outer

If the burn was on the right knee what was its depth? (notes, staff, researcher observation)

- Superficial
- Partial
- Full Thickness
- Mixed

Has the wound on the right knee healed? (notes, staff, researcher observation)

- Yes
- No
- Don't know

If it has, when did it heal? (notes, staff, researcher observation)

- >3 weeks
- 3-6 weeks
- >6weeks

Has the right knee been grafted? (notes, staff, researcher observation)

- Yes
- No
- Failed

Is there a splint on the right knee? (notes, patient, staff, researcher observation)

- Yes
- No
- Don't know

Was the burn injury on left knee? (notes, patient, staff, researcher observation)

- None
- anterior
- posterior
- inner
- outer

If the burn was on the left knee what was its depth? (notes, staff, researcher observation)

- Superficial
- Partial
- Full Thickness
- Mixed

Has the wound on the left knee healed? (notes, staff, researcher observation)

- Yes
- No
- Don't know

If it has, when did it heal? (notes, staff, researcher observation)

- >3 weeks
- 3-6 weeks
- >6weeks

Has the left knee been grafted? (notes, staff, researcher observation)

- Yes
- No
- Failed

Is there a splint on the left knee?

- Yes
- No
- Don't know

Was the burn injury on right ankle? (notes, patient, staff, researcher observation)

- None
- anterior
- posterior
- inner
- outer

If the burn was on the right ankle what was its depth? (notes, staff, researcher observation)

- Superficial
- Partial
- Full Thickness
- Mixed

Has the wound on the right ankle healed? (notes, staff, researcher observation)

- Yes
- No
- Don't know

If it has, when did it heal? (notes, staff, researcher observation)

- >3 weeks
- 3-6 weeks
- >6weeks

Has the right ankle been grafted? (notes, staff, researcher observation)

- Yes
- No
- Failed

Is there a splint on the right ankle?

- Yes
- No
- Don't know

Was the burn injury on left ankle? (notes, patient, staff, researcher observation)

- None
- anterior
- posterior
- Inner
- outer

If the burn was on the left ankle what was its depth? (notes, staff, researcher observation)

- Superficial
- Partial
- Full Thickness
- Mixed

Has the wound on the left ankle healed? (notes, staff, researcher observation)

- Yes
- No
- Don't know

If it has, when did it heal? (notes, staff, researcher observation)

- >3 weeks
- 3-6 weeks
- >6weeks

Has the left ankle been grafted? (notes, staff, researcher observation)

- Yes
- No
- Failed

Is there a splint on the left ankle?

- Yes
- No
- Don't know

Was the burn injury on the face? (notes, staff, researcher observation)

- Yes
- No
- Don't know

Is there a contracture of the face?

- Yes
- No
- Don't know

If yes, where are the facial contractures?

- Ectropian Right
- Ectropian Left
- Nasal Right
- Nasal Left
- Oral Upper
- Oral Lower
- Oral Right Side
- Oral Left Side

Was the burn injury on the hand? (notes, staff, researcher observation)

- None
- One hand
- Both hands

Is there a contracture to the right hand?

- Yes
- No
- Don't know

If yes, where is the hand contracture on the right hand?

- 1
- 2
- 3
- 4
- 5

Is there a contracture to the left hand?

- Yes
- No
- Don't know

If yes, where is the hand contracture on the left hand?

- 1
- 2
- 3
- 4
- 5

Was the burn injury on the toes? (notes, staff, researcher observation)

- None
- One hand
- Both hands

Is there a contracture to the right toes?

- Yes
- No
- Don't know

If yes, where are the contracture on the right toes?

- 1
- 2
- 3
- 4
- 5

Is there a contracture to the left toes?

- Yes
- No
- Don't know

If yes, where are the contracture on the left toes?

- 1
- 2
- 3
- 4
- 5

Approximately what percentage of the TBSA has healed? (notes, staff, researcher observation)

ABOUT THE PATIENT

If Yes, then how has it affected your mental health? (researcher asks patient and staff)

Are there any comorbidities (Physical or Psychological? (notes, staff, patient, researcher observation)

- Yes
- No
- Don't know

Is there any evidence of co-morbidities or physical or psychological past medical history? (notes, staff, patient, researcher observation)

- Mental Health
- Diabetes
- Pathology Reducing Joint Range of Movement
- Neurological deficit
- Other

Has the patient lost significant weight since admission? (notes, staff, patient, researcher observation)

- Yes
- No
- Don't know

Does patient have amputated limbs? (researcher observation)

- Yes
- No
- Don't know

If yes, where? (researcher observation)

Does patient have neuropathy? (notes, patient, researcher observation)

- Yes
- No
- Don't know

If yes, then where? (notes, patient, researcher observation)

Does the patient have any hypertrophic ossification? (notes, patient, researcher observation)

- Yes
- No
- Don't know

If yes, where? (notes, patient, researcher observation)

TREATMENT: Physiotherapy, Pain Management, Surgery, Dressing, Diet and Education and Adherence

Have you been seen by a physiotherapist or occupational therapist? (notes, patient, staff)

- Yes
- No
- Don't know

If the patient does have physiotherapy - how many times a week do you see a physiotherapist? (notes, patient, staff)

- Everyday
- Once a week
- Twice a week
- Other

About how long is each visit from the therapist? (notes, patient, staff)

- 10 minutes
- 30 minutes
- 1 hour
- Other

Can you walk? (notes, patient, staff)

- Yes
- No
- Don't know

Do you walk to the toilet? (notes, patient, staff)

- Yes
- No
- Don't know

Does anything stop you moving? Prompt - e.g. getting out of bed (researcher asks patient)

- Nothing limits my movement
- Pain
- Dressings
- Mood
- Other
- Don't know

Can the patient demonstrate any exercises that will help prevent or treat a contracture? (researcher observes and asks patients)

- Yes
- No
- Ineffective

Can the patient tell us any advice they have been given to help prevent or treat their contractures, if so what? (researcher asks patient)

- Yes
- No
- Don't know

Describe and comment on the advice**Is the splint effective? (researcher observes)**

- Yes
- No
- Don't know

Note where the splint has been placed and wearing regime i.e. frequency, length of time etc.) (researcher observes)**Does the patient understand why they are wearing a splint? (researcher asks patient)****How does the patient position the burned limb / area? (researcher observes and asks patient)**

Does the patient understand the importance of anti contracture or oedema reduction positioning? (researcher asks patient)

Is there oedema of an affected area? (researcher observes)

- Yes
- No
- Don't know

Is any compression provided for the burn area? (researcher observes)

- Yes
- No
- Don't know

Does the patient have a pressure garment? (researcher observes)

- Yes
- No
- Don't know

What is the patients experience of pain during their hospital stay? ((researcher asks patient and staff)

What is the patients visual analog scale for pain, right now? (researcher asks patient)

- No Pain
- One
- Two
- Three
- Four
- Five
- Six
- Seven
- Eight
- Nine
- Ten

What is the patients visual analog scale for pain, on average? (researcher asks patient)

- No Pain
- One
- Two
- Three
- Four
- Five
- Six
- Seven
- Eight
- Nine
- Ten

What pain medications is the patient on and how often do they take the pain medication? (notes, patient, staff, researcher observation of chart)

What level of pain threshold does the patient report? (researcher asks patient and staff)

- None
- Low
- Medium
- High

Describe pain threshold in text here if needed.

Has the patient got any wound infections?

- Yes
- No
- Don't know

Does the patient get fed with an NG tube? (notes, patient, staff, researcher observation)

- Yes
- No
- Don't know

What is the patients daily diet like? (notes, patient, staff)

Has the patient been given any advice from staff on what they need to do to improve/ get better? Prompt - please explain any advice you have been given, prompt for advice relevant to contracture formation (researcher asks patient)

Is the patient following the advice given? (researcher asks patient)

Has the patient been in critical care? (notes, staff)

- Yes
- No
- Don't know

I am looking at factors that may have caused contractures – what do you think I should be look at to discover this? (researcher asks patient)

Final Observations (Audio)

Click here to upload file. (< 5MB)

Final Observations (Text)

Has the patient been given any advice from staff on what they need to do to improve/ get better? Prompt - please explain any advice you have been given, prompt for advice relevant to contracture formation (researcher asks patient)

Is the patient following the advice given? (researcher asks patient)

Has the patient been in critical care? (notes, staff)

- Yes
- No
- Don't know

I am looking at factors that may have caused contractures – what do you think I should be look at to discover this? (researcher asks patient)

Final Observations (Audio)

Click here to upload file. (< 5MB)

Final Observations (Text)

APPENDIX 8: RECONSTRUCTIVE INTERVIEW GUIDE PILOT STUDY

2/18/2019

Reconstructive_Patients_Form

Employment at time of injury (patient)

- Unemployed
- Not paid/House work
- Self Employed
- Informal Employment
- Formal Employment
- Student
- Other

If other employment, fill in text box.

Income Level (patient, staff)

- No Income
- <£300 per year
- £300-£1000 per year
- £1000- £5000 per year
- >£5000 per year
- Other

If other income , fill in text box.

Rural/Urban (patient)

- Rural
- Urban
- Semi Urban

Ethnicity (Only ask if not Bangladeshi) (researcher)

- Bangladeshi
- Other

Ethnicity if not Bangladeshi

PATIENT OPINION

Can you tell me why you are in hospital? (researcher to patient)

Do you have a name for this (point at contracture), the tightness that stops you fully moving your (name joint or body part)? (researcher to patient)

- Yes
- No
- Don't know

If yes, what do you call it? (researcher to patient)

Have you heard of the word 'contracture' (using local medical term)? (researcher to patient)

- Yes
- No
- Don't know

If yes, what do you think it means? (researcher to patient)

Why do you think you have a contracture (what has caused the contracture)? (researcher to patient)

Can you tell me what happened from the moment you got the burn to the time you went for treatment? (researcher to patient and significant other)

Recording of patient's account of burn injury incident to treatment.

Click here to upload file. (< 5MB)

Can you tell me what you remember of the treatment you had? (researcher to patient and significant other)

Recording of patient's account of treatment

Click here to upload file. (< 5MB)

Can you tell me what you remember about what happened after treatment? (researcher to patient and significant other)

Recording of patient's experience after treatment

Click here to upload file. (< 5MB)

Can you think of anything that you think made the contracture better (clarify better as appropriate e.g. less stiff)? (researcher to patient and significant other)

- Yes
- No
- Don't know

Can you think of anything that made your contracture better (clarify better as appropriate e.g. less stiff) ? (researcher to patient and significant other)

Can you think of anything that made your contracture worse (clarify better as appropriate e.g. more stiff)? (researcher to patient and significant other)

- Yes
- No
- Don't know

Can you think of anything that made your contracture worse (clarify better as appropriate e.g. more stiff)? (researcher to patient and significant other)

Do you think your contracture could be prevented (explain prevented)? (researcher to patient and significant other)

- Yes
- No
- Don't know

If no, why not? (researcher to patient and significant other)

If yes, how could it have been prevented? (researcher to patient and significant other)

Did you know when you had the burn that you may develop a contracture? (researcher to patient and significant other)

- Yes
- No
- Don't know

HEALTH CARE SYSTEM: First Aid, Finance and Follow up (new info is collected in this section only if not given in interview above, if answers to these questions have been given above, confirmation of the info only is done at this stage i.e. researcher inputs from the previous info and patient confirms)

When the burn happened what did you do immediately? Prompts - did you remove your clothes, did you put anything on the burn, how long after the burn did you do these things, if you applied water how long for? (Researcher asks patient)

Was the first treatment appropriate? (Researcher decides based provided information in comparison to evidence base)

- Yes
- No
- Don't know

How many days (or weeks) was it between the time you got the burn injury and the time that you went for treatment? (Notes, Researcher asks patient)

- Same day
- Next day
- Within 5 days
- 5 days- 2 wks
- 2wks- 1 month
- 1month - 2months
- > 2 months
- Other

Where (what person/place) was the first treatment? (Notes, Researcher asks patient)

- Traditional Medicine
- Friend
- Medical University,
- Medical College Hospitals
- Specialized Hospitals
- District Hospitals
- Mother and Child Welfare Centers
- Upazila (Sub District) Health Complex,
- Union Health & Family Welfare Centers,
- Community Clinics
- Non-Government Organization
- Private Institutions
- Other

If other, where did they go first? (Notes, Researcher asks patient)

If you came to this hospital (NIBPS) how many days (or weeks) was it before you came to this hospital? (Notes, Researcher asks patient)

- Same day
- Next day
- Within 5 days
- 5 days- 2 wks
- 2wks- 1 month
- 1month - 2months
- > 2 months
- Other

Why could you not get treatment more quickly? (Only ask if not on same day) (Notes, Researcher asks patient)

How did you travel to the hospital? (Notes, Researcher asks patient)

- Walking
- Bicycle
- Animal
- Motor Bike
- Three Wheelers
- Public Bus/Minivan
- Train
- Taxi
- Private Vehicle
- Ambulance
- Other

If other travel mode , fill in text box.

Distance from home to first treatment centre (researcher asks patient)

- < 1hour
- 1- 3 hours
- 3- 6 hours
- >6 hours

Distance of home from Dhaka (researcher asks patient)

- < 1hour
- 1- 3 hours
- 3- 6 hours
- >6 hours

How far was the journey to the hospital in kilometres? (researcher asks patient)**Did you have to pay for any aspects of your ACUTE care?(researcher to patient and significant other)**

- Yes
- No
- Don't know

If yes, what do you have to pay for? (researcher to patient and significant other)

- Operation
- Dressing Materials
- Dressing Procedure
- Pain Medication
- Antibiotics
- Other Medication
- Food
- Splints
- Therapist
- Other

If they had to pay for other aspect of care not on the list, what were they? (researcher to patient and significant other)**Was there any treatment that you were told that you needed but you have decided not to have because you don't have the money for it? (researcher to patient and significant other)**

- Yes
- No
- Don't know

If yes, what treatment were you told that you needed that you don't have money for? (researcher to patient and significant other)

- Operation
- Dressing Materials
- Dressing Procedure
- Pain Medication
- Antibiotics
- Other Medication
- Food
- Splints
- Therapist
- Other

If there are other treatments not listed in the categories that you were told you needed that you couldn't pay for, what were they exactly? (researcher to patient and significant other)

How long were you in hospital?(Notes, Researcher asks patient)

- <1 month
- 1-2 months
- 2-4 months
- Other

Additional notes on length of stay (Researcher)

For what reason did you leave hospital? (Notes, Researcher asks patient)

Did you know what to do about looking after your injury when you left hospital? (researcher asks patient)

- Yes
- No
- Don't know

If yes, what? (researcher asks patient)

Did you have any further treatment for your injury after leaving hospital? (researcher asks patient)

- Yes
- No
- Don't know

If so, where and what? (researcher asks patient)

Were all your wounds healed by the time you left hospital? (researcher asks patient)

- Yes
- No
- Don't know

How much could you move the affected joint when you left hospital? (researcher asks patient - patient demonstrates)

- Mild
- Moderate
- Severe
- Don't know

Can you remember how long it took for all your wounds to heal? (researcher asks patient)

- Yes
- No
- Don't know

If yes, how long did they take to heal? (researcher asks patient)

- <1 month
- 1-2 months
- 2-4 months
- Other

Additional notes on healing time (Researcher)

Did the contracture get worse or better after you went home? (researcher asks patient)

- No difference
- Better
- Worse
- Do not know

How did you get the appointment to come here for your operation? (researcher asks patient)

ABOUT THE BURN INJURY

Date of burn (notes and patient)

yyyy-mm-dd

What caused the burn injury? (select one from list) (notes and patient)

- Flame
- Hot Surface
- Hot liquid, steam or gas
- Electrical
- Chemical
- Friction
- Inhalation
- Cooling
- Radiation
- Other

Was the burn injury intentional? (notes and patient - patient is not asked directly - box is ticked only if in notes or offered by patient in history)

- Yes
- No
- Don't know

Total Body Surface Area of Burn (TBSA) (to the nearest full percentage) (notes)

Associated smoke inhalation injury (notes and patient is asked)

- Yes
- No
- Don't know

What is the depth of the burn overall? (notes and researcher - looking at extent of scarring)

- Superficial
- Partial
- Full Thickness
- Mixed

Was the burn injury on the neck? (notes, researcher observation)

- None
- Front
- Back
- 1 Side
- 2 Sides

Was the burn injury on the right shoulder? (notes, researcher observation)

- None
- Top
- Dome
- Inner
- Outer

Was the burn injury on the left shoulder? (notes, researcher observation)

- None
- Top
- Dome
- Inner
- Outer

Was the burn injury on the right elbow? (note, researcher observation)

- None
- anterior
- posterior
- Inner
- outer

Was the burn injury on the left elbow? (note, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Was the burn injury on the right wrist? (note, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Was the burn injury on the right wrist? (note, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Was the burn injury on right hip? (notes, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Was the burn injury on left hip? (notes, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Was the burn injury on right knee? (notes, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Was the burn injury on left knee? (notes, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Was the burn injury on right ankle? (notes, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Was the burn injury on left ankle? (notes, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Was the burn injury on the face? (notes, researcher observation)

- Yes
- No
- Don't know

Was the burn injury on the hand? (notes, researcher observation)

- None
- One hand
- Both hands

ABOUT THE PATIENT

If Yes, then how has it affected your mental health? (researcher asks patient)

Is there any evidence of co-morbidities or physical or psychological past medical history? (notes, patient, researcher observation)

- Mental Health
- Diabetes
- Pathology Reducing Joint Range of Movement
- Neurological deficit
- Other

If other comorbidity or pathology reducing range of movement, add more info here?

Does patient have amputated limbs? (researcher observation)

- Yes
- No
- Don't know

If yes, where? (researcher observation)

Does patient have neuropathy? (notes, patient, researcher observation)

- Yes
- No
- Don't know

If yes, then where? (notes, patient, researcher observation)

Does the patient have any hypertrophic ossification? (notes, patient, researcher observation)

- Yes
- No
- Don't know

If yes, where? (notes, patient, researcher observation)

TREATMENT: Physiotherapy, Pain Management, Surgery, Dressing, Diet and Education and Adherence

Can the patient remember if they saw a physio therapist? (researcher asks patient)

- Yes
- No
- Don't know

If they can, what can they tell you about the therapy that they had? (researcher asks patient)

Did the patient do any exercises to move and stretch their limbs? If so explore (researcher asks patient, patient demonstrates)

- Yes
- No
- Ineffective
- Yes
- No
- Inadequate
- Do not know

Additional information on exercises done by patient

Can the patient remember any position they held their affected limb in? (researcher asks patient, patient demonstrates)

- Yes
- No
- Ineffective
- Yes
- No
- Inadequate
- Do not know

Can they remember if they were mobile during their treatment? Prompt - e.g. able to get out of bed (researcher asks patient)

- Yes
- No
- Don't know

Did the patient have a splint? (researcher asks patient)

- Yes
- No
- Don't know

If the patient had a splint then have patient explain the splint e.g.what kind of splint, how often and how long they wore it for? (researcher asks patient)

Does it appear that the splints were appropriate and effective? (researcher decides based on information provided)

- Appropriate
- Not Appropriate
- Do not know

Did the patient use pressure garments? (researcher asks patient)

- Yes
- No
- Don't know

If the patient had a pressure garment then have patient explain which garments they had and how long they wore them for? (researcher asks patient)

Does it appear that the pressure garments were appropriate and effective? (researcher decides based on information provided)

- Appropriate
- Not Appropriate
- Do not know

Did the patient have any scar massage? (researcher asks patient)

- Yes
- No
- Don't know

If the patient had a scar massage, then have patient demonstrate how the massage was done and how long they did it for? (researcher asks patient)

Does it appear that the scar massage was appropriate and effective? (researcher decides based on information provided)

- Appropriate
- Not Appropriate
- Do not know

What was the patients experience of pain during their hospital stay? (researcher asks patient)

What level of pain threshold does the patient report at the time of the injury/treatment? (researcher asks patient)

- None
- Low
- Medium
- High

Did the patient have any skin grafting? (notes, patient, researcher observation)

- Yes
- No
- Don't know

Was the grafting done on the neck? (notes, patient, researcher observation)

- None
- Front
- Back
- 1 Side
- 2 Sides

Was the grafting done on the right shoulder? (notes, patient, researcher observation)

- None
- Top
- Dome
- Inner
- Outer

Was the grafting done on the left shoulder? (notes, patient, researcher observation)

- None
- Top
- Dome
- Inner
- Outer

Was the grafting done on right hip? (notes, patient, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Was the grafting done on left hip? (notes, patient, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Was the grafting done on right knee? (notes, patient, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Was the grafting done on left knee? (notes, patient, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Was the grafting done on ankle? (notes, patient, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Was the grafting done on left ankle? (notes, patient, researcher observation)

- None
- anterior
- posterior
- inner
- outer

Did the operation work (did the skin take)? (notes, patient, researcher observation)

- Yes
- No
- Don't know

Space for text if more than one location needs explanation regarding success/failure (researcher asks patient)

Were you offered an operation but refused to have it? (notes, patient)

- Yes
- No
- Don't know

If the patient refused operation, why did they refuse? (notes, patient)

Can the patient remember if they had any infection during their hospital stay? (notes, researcher asks patient)

- Yes
- No
- Don't know

Does the patient remember if they had NG feeding during their treatment? (notes, patient)

- Yes
- No
- Don't know

Did the patient loose a lot of weight during the treatment of the burn (patient)

- Yes
- No
- Don't know

Can you remember any advice you were given during your treatment? (patient)

- Yes
- No
- Don't know

If yes, what advice were you given? And did you follow this advice? (patient)

APPENDIX 9: CONTRACTURE MEASUREMENT FORM PILOT STUDY

Using the Shoulder Joint as an Example (a form was developed for each joint location)

2/7/2019

Contracture_Measurement_Form_Shoulder

Contracture_Measurement_Form_Shoulder

This is a child form that links to the parent forms Acute and Recon. It is comprised solely of data from patients with contracture. Unit of analysis is measurement of each muscle action in the joint defined by the form name. A new blank form should be filled in for EVERY new muscle action being measured.

Today's Date

yyyy-mm-dd

CONTRACTURE LOCATION

Patient number

Study No

On which side of the body is the shoulder?

- Right
- Left
- Neck

Picture 1 of contracture at joint

Click here to upload file. (< 5MB)

Picture 2 of contracture at joint

Click here to upload file. (< 5MB)

Picture 3 of contracture at joint

Click here to upload file. (< 5MB)

Picture 4 of contracture at joint

Click here to upload file. (< 5MB)

CONTRACTURE MEASURMENT

On which muscle action is the measurement to be taken?

- Flexion
- Extension
- Abduction
- Adduction
- External Rotation
- Internal Rotation

Active ROM Assessor 1

Active ROM Assessor 2

Active ROM App1

Active ROM App2

Passive ROM Assessor 1

Passive ROM Assessor 2

Passive ROM App1

Passive ROM App2

ADDITIONAL OBSERVATIONS

Are there other factors that may be contributing to reduced ROM other than scarring?

- None
- Pain
- Chronic condition
- Dressings
- Fear
- Other

Additional comments from researcher on these measurements

Audio recording of additional comments

Click here to upload file. (< 5MB)

APPENDIX 10: PARTICIPANT INFORMATION SHEET PILOT STUDY

(on Swansea University Headed paper)

This form will be translated into written Bangla and be read to the participant in Bangla

Identification of Risk Factors in the Formation of Burn Contractures

You are being invited to take part in some research. Before you decide whether to participate, it is important for you to understand why the research is being conducted and what it will involve. Please read or listen to the following information carefully. Please tell us if there is something that you do not understand or if you have any questions.

What is the purpose of the research?

Scarring after a burn injury is common. The research team has an interest in preventing scarring that limits the movement of joints. You have been invited to be involved in the study because you have had a burn injury. Whether you have scarring or not and if you do whether the scarring limits your movements or not, we would like to learn from your experience and opinions. To do this we will ask you some questions about what happened after you had the burn injury and about your treatment. No answer is right or wrong, we are only interested in your opinion and your experience. Through this research and with your help we aim to help people who have had a burn injury keep good movement and function even if they have scarring.

Who is carrying out the research?

The data are being collected by RuthAnn Fanstone, PhD student from the Global Centre for Burn Injuries Policy and Research, Swansea University, UK. The research has been approved by the College of Human and Health Sciences Research Ethics Committee.

What happens if I agree to take part?

After reading this information and having it explained to you, the researcher will check that you understand the information and that you are happy to be part of the study. You should only agree to be involved with the study if you want to, no one should put any pressure on you to be involved – it is your decision. Once you think you would like to be involved to make sure everything is clear to you, you will be asked to sign or speak your consent or agreement to each point on the consent form (a separate form that the researcher will give you and talk to you about). The consent form gives us a record to show us that you understand your involvement in the study and that you agree to it.

As well as your involvement being fully optional, you can decide to stop being a part of the research at any time. You will have until we leave your bedside, after collecting all the information from you to withdraw all your information from the study. Not taking part in this study or stopping your involvement in the study will not affect your care or disadvantage you in anyway. The research team have no connection to your treatment and are not involved in any decisions about your clinical care. The hospital staff looking after your care will not be told if you do not agree to take part in the study and they will not be given any information that you share with us in the discussion.

We will collect some of the information from your medical notes, but mainly we would like to ask you some questions. We will ask you questions such as 'can you tell us how you got the burn', how long did it take to travel to the hospital for treatment' 'are you taking medication for pain, if so please tell us more about this'. We will ask you at what time of day is best for you to give your time to the questions we have for you. Two of us will sit with you, both of us understand about burn care treatment. One of the two people can only speak English and therefore they need help from a translator.

We will put the information you give us from your answers into a tablet (explain and show) while we sit with you. It may take about 45 minutes to ask you the questions. You can stop the interview at any time and you do not have to answer any question that you do not want to answer. If you do have scarring or a wound that limits your movement, the researchers will ask you if they can measure the affected joint. We will ask you to move your joint in a certain direction, for example straighten your elbow. We will take three measures – two with this instrument (show goniometer) and one by taking a photo with this phone (show them how the App works). A final measure is taken when the researcher gently holds your limb and sees if they can stretch it slightly further. If this is too painful for you the researcher will stop the movement (demonstrate a movement). We will also ask you if you agree for us to take a photo of the joint that is not moving fully, we will not include your face in the photo.

Are there any risks associated with taking part?

The research has been approved by the College of Human and Health Sciences Research Ethics Committee. There are no significant risks associated with participation.

It may be possible that discussing details of your burn injury, may cause you anxiety or distress. If so then we have made provision for you to access psychological and counselling support by the clinical psychology team on Dhaka University. Please discuss with the research team when they are interviewing you if you would like to access these services.

Data Protection and Confidentiality

Your data will be processed in accordance with the Data Protection Act 2018 and the General Data Protection Regulation 2016 (GDPR). All information collected about you

will be kept strictly confidential. The researcher/research team will only view your data.

All electronic data will be stored on a password-protected computer file on the researcher's encrypted laptop and on the personal desktop of the researcher in Swansea University. All paper records will be stored in a locked filing cabinet in the office at Swansea University. Your consent information will be kept separately from your responses to minimise risk in the event of a data breach.

Please note that the data we will collect for our study will be made anonymous from the start thus it will not be possible to identify and remove your data at a later date, should you decide to withdraw from the study. Therefore, if at the end of this research you decide to have your data withdrawn, please let us know before we finish.

What this means for you is that the information that we collect from you will only be available to the research team and they will look after it with great care to make sure no one else can see it. Any information they use from this study will not be connected to you individually, your name will not appear on any of the information collected.

Conducting research overseas

The researchers will abide by local data protection laws when collecting personal data.

What will happen to the information I provide?

An analysis of the information will form part of our report at the end of the study and may be presented to interested parties and published in scientific journals and related media. Note that all information presented in any reports or publications will be anonymous and unidentifiable.

Is participation voluntary and what if I wish to later withdraw?

Your participation is entirely voluntary – you do not have to participate if you do not want to. If you decide to participate, but then wish to withdraw from the study then you can do this. You will have until we leave your bedside, after collecting all the information from you to withdraw all your information from the study. You do not have to give a reason for withdrawing and it will not impact on your care.

Data Protection Privacy Notice

The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data, and can be contacted at the Vice Chancellors Office.

Your personal data will be processed for the purposes outlined in this information sheet. Standard ethical procedures will involve you providing your consent to

participate in this study by completing the consent form that has been provided to you.

The legal basis that we will rely on to process your personal data will be processing is necessary for the performance of a task carried out in the public interest. This public interest justification is approved by the College of Human and Health Sciences Research Ethics Committee, Swansea University.

The legal basis that we will rely on to process special categories of data will be processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

How long will your information be held?

We will hold any personal data and special categories of data for ten years as stipulated by Swansea University.

What are your rights?

You have a right to access your personal information, to object to the processing of your personal information, to rectify, to erase, to restrict and to port your personal information. Please visit the University Data Protection webpages for further information in relation to your rights.

Any requests or objections should be made in writing to the University Data Protection Officer: -

University Compliance Officer (FOI/DP)
Vice-Chancellor's Office
Swansea University
Singleton Park
Swansea
SA2 8PP
Email : dataprotection@swansea.ac.uk

How to make a complaint

If you are unhappy with the way in which your personal data has been processed you may in the first instance contact the University Data Protection Officer using the contact details above.

If you remain dissatisfied then you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: -
Information Commissioner's Office,
Wycliffe House,
Water Lane,
Wilmslow,
Cheshire,
SK9 5AF
www.ico.org.uk

What if I have other questions?

If you have further questions about this study, please do not hesitate to contact us:

RuthAnn Fanstone
Global Centre for Burn Injuries
Policy and Research
Swansea University

[REDACTED]

Professor Tom Potokar
Global Centre for Burn Injuries
Policy and Research
Swansea University

E: [REDACTED]

APPENDIX 11: PARTICIPANT CONSENT FORM PILOT STUDY

(on Swansea University Headed paper)

This form will be translated into written Bangla and be read to the participant in Bangla

Identification of the Risk Factors for Burn Contracture Formation

Principal Researcher – RuthAnn Fanstone, PhD Candidate, Global Centre for Burn Injuries Policy and Research, Swansea University, Swansea, SA2 8PP, Wales

I (the participant) confirm that I have read and understand the information sheet for the above study (dated) which is attached to this form.
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons.
I understand what my role will be in this research, and all my questions have been answered to my satisfaction.
I understand that I am free to ask any questions at any time before and during the study.
I have been informed that the information I provide will be safeguarded.
I am happy for the information I provide to be used (anonymously) in academic papers and other formal research outputs.
I am willing for my information to be audio recorded.
I am willing for the researcher to look at my medical notes
I have been provided with a copy of the Participant Information Sheet.
I agree to the researchers processing my personal data in accordance with the aims of the study described in the Participant Information Sheet.

Thank you for your participation in this study. Your help is very much appreciated.

Print name of participant

Signature

Date

Print name of researcher

Signature

Date

This study is being conducted by Swansea University, College of Human and Health Science.

When complete: Original copy for the participant, one copy to be retained by researcher

APPENDIX 12: PARTICIPANT INFORMATION SHEET FGD

(on Swansea University Headed paper)

This form will be translated into written Bangla and be read to the participant in Bangla

Identification of Risk Factors in the Formation of Burn Contractures

You are being invited to take part in some research about your burn injury. Before you decide whether to participate, it is important for you to understand why the research is being conducted and what it will involve. Please read and listen to the following information carefully. Please tell us if there is something that you do not understand or if you have any questions.

What is the purpose of the research?

Scarring after a burn injury is common and can make life difficult. The research team has an interest in preventing scarring that limits the movement of joints and would like to learn from your experience and opinions.

You have been asked to be involved in this study because you have had an experience, as an adult, of a burn injury that has caused scarring which limits some of your movement. We are interested to know what words and terms you use to describe the scarring that limits the movement of your joints. We would also like to know why you believe you developed loss of movement due to the scarring and what you can remember about the experience of the injury and the treatment. For example, we will ask you questions such as 'can you tell me what you remember of the time you had your injury and what happened from that point until the time you went for treatment', 'can you remember if you had an operation for your burn injury, if so please tell us about that'. No answer is right or wrong, we are only interested in your opinion and your experience. We will ask not only you these questions but we will ask the group that you will be in with which includes five other people who have had a burn injury. You can say as much or as little about your experience as you are comfortable to say within the group. We hope the more we understand about how and why scars develop the more we can do to help us prevent other people having problematic scars.

What we learn from you in this research we will use to develop questions to ask other patients and will help us decide what aspects of burn care to look at so that we can understand what are the main factors that affect the development of scarring that limits movement.

Who is carrying out the research?

The data are being collected by RuthAnn Fanstone, PhD student from the Centre for Global Burn Injury Policy and Research, Swansea University, UK. The research has been approved by the Swansea University Ethics Committee.

What happens if I agree to take part?

After reading this information and having it explained to you, the researcher will check that you understand the information and that you are happy to be part of the study. You should only agree to be involved with the study if you want to be, no one should put any pressure on you to be involved – it is your decision. Once you think you would like to be involved, to make sure everything is clear to you, you will be asked to sign or speak your consent or agreement to each point on the consent form (a separate form that the researcher will give you and talk to you about). The consent form gives us a record to show us that you understand your involvement in the study and that you agree to it.

As well as your involvement being optional, you can decide to stop being a part of the research at any time during the discussion. You will have up to when you leave the hospital following the discussion to withdraw yourself and your comments from the study. Not taking part in this study or stopping your involvement in the study will not affect your care for your burn injury or disadvantage you in anyway. The research team have no connection to your treatment and are not involved in any decisions about your clinical care. The hospital staff looking after your care will not be told if you do not agree to take part in the study and they will not be given any information that you share with us in the discussion.

We will meet at xxx (time) today in a private room in the outpatient department of this hospital. We ask that you attend alone and your family or friends wait for you outside. We will sit in a circle to have a discussion. A facilitator who will have some questions to guide the conversation will lead the discussion. In the group, there will be five other people who have experience of burn scars who will also share their experiences. Also in the room will be two other researchers. We would like to hear about what you remember about the injury and the treatment you had. Mostly, we would like to understand why you think you developed the scarring that limits your movement. The discussion is likely to take one and half-hours. The discussion will be recorded so that we can capture all your thoughts and ideas and use them in the research. Your thoughts and ideas will not be identifiable to you.

The benefit of being part of this study is that you can share your experiences with others and maybe learn from others experiences. You will be helping the research team learn from your experiences so that we can better understand why scarring can limit movement so we can try to prevent this happening to others. We will provide a snack box for you and for anyone who is waiting with you.

Are there any risks associated with taking part?

The research has been approved by the University Ethics Committee. There are no significant risks associated with participation.

It may be possible that discussing details of your burn injury and hearing the story of other burn survivors as part of the group, may cause you anxiety or distress. If so then we have made provision for you to access psychological and counselling support by the clinical psychology team on Dhaka University. Please discuss with the research team if you would like to access these services.

Data Protection and Confidentiality

Your data will be processed in accordance with the Data Protection Act 2018 and the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. The researcher/research team will only view your data.

All electronic data will be stored on a password-protected computer file on the researcher's encrypted laptop and on the personal desktop of the researcher in Swansea University. All paper records will be stored in a locked filing cabinet in the researcher's office at Swansea University. Your consent information will be kept separately from your responses to minimise risk in the event of a data breach.

Please note that the data we will collect for our study will be made anonymous from the start so it will not be possible to identify and remove your data later, should you decide to withdraw from the study. Therefore, if at the end of the discussion you decide to have your data withdrawn, please let us know before you leave.

What this means for you is that no one outside the room where we have the discussion, other than the research team, will know what you have said in any way that can be connected with your personally. We will not use your name in connection with anything you have said. You should also not speak about anything shared by the others in our group other people, so that each member of the group is confident that what they are sharing will not be told to others. The recording that we take of the discussion will be kept safe so only the research team will have access to it.

Conducting research overseas

The researchers will abide by local data protection laws when collecting personal data.

What will happen to the information I provide?

An analysis of the information will form part of our report at the end of the study and may be presented to interested parties and published in scientific journals and related

media. Note that all information presented in any reports or publications will be anonymous and unidentifiable.

Is participation voluntary and what if I wish to later withdraw?

Your participation is entirely voluntary – you do not have to participate if you do not want to. If you decide to participate, but later wish to withdraw from the study, this can happen at any time. However, as you have agreed to be recorded your comments will be included in the analysis unless you notify us before you leave the hospital, following the discussion. You do not need to give us any reason for your withdrawal and it will not have any impact on your care.

Data Protection Privacy Notice

The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data, and can be contacted at the Vice Chancellors Office.

Your personal data will be processed for the purposes outlined in this information sheet.

Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you.

The legal basis that we will rely on to process your personal data will be necessary for the performance of a task carried out in the public interest. This public interest justification is approved by the College of Human and Health Sciences Research Ethics Committee, Swansea University.

The legal basis that we will rely on to process special categories of data will be necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

How long will your information be held?

We will hold any personal data and special categories of data for ten years as stipulated by Swansea University.

What are your rights?

You have a right to access your personal information, to object to the processing of your personal information, to rectify, to erase, to restrict and to port your personal information. Please visit the University Data Protection webpages for further information in relation to your rights.

Any requests or objections should be made in writing to the University Data Protection Officer: -

University Compliance Officer (FOI/DP)

Vice-Chancellor's Office
Swansea University
Singleton Park
Swansea
SA2 8PP
Email : dataprotection@swansea.ac.uk

How to make a complaint

If you are unhappy with the way in which your personal data has been processed you may in the first instance contact the University Data Protection Officer using the contact details above.

If you remain dissatisfied then you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: -

Information Commissioner's Office,
Wycliffe House,
Water Lane,
Wilmslow,
Cheshire,
SK9 5AF
www.ico.org.uk

What if I have other questions?

If you have further questions about this study, please do not hesitate to contact us:

RuthAnn Fanstone
Global Centre for Burn Injuries
Policy and Research
Swansea University

Professor Tom Potokar
Global Centre for Burn Injuries Policy
and Research
Swansea University

[E:](#)

APPENDIX 13: CONTRACTURE MEASUREMENT PROTOCOL (PILOT)

1. Inform and consent participant as per protocol
2. Following the interview explain again the process of joint contracture measurement. Again, ask for consent for the photographs of joint from the participant and carer.
3. Ensure the environment is appropriate for all the joint measurements required, e.g., consider amount of skin exposure required and privacy of the space, consider availability of a bed. Ask the participant who she/he would like in the room for the measurement, other than the researcher and the translator. Confirm she is comfortable with the presence of the translator (if male).
4. Assess all areas where there is scarring and determine from the scarring which joints were at risk of contracture.
5. Count and document the number of major joints that are contracted and the number at risk but not contracted.
6. Assess and document if there are any confounders to joint movement (anything affecting range of a joint other than burn/scar contracture).
7. Any joints with pre-existing loss of movement (ask the participant), or with a contraindication to movement such as recent grafting, or which had undergone previous reconstruction, are excluded.
8. Briefly assess each affected joint (contracted and not contracted) for active and passive movement by requesting movement through each joint at risk. The researcher demonstrates the movement on herself, the translator also demonstrates the movement on his/herself and explains active and passive movement. The participant is reassured that the measurement should not cause any pain and will not be more than she / or he can tolerate. At any point the movement / measurement can be stopped.
9. Position the participant appropriately as per measurement chart for the first joint to be measured

Following points below are followed for each included joint at risk:

10. If there was full range of movement at a joint at risk, as assessed by researcher observation, measurement with a goniometer was not taken and full ROM

was documented. If the researcher was in doubt as to whether full ROM was available at a specific joint, a goniometer measurement was taken. Movement on one side of the body, was compared to the other if the contralateral side was not a joint at risk i.e., if the left wrist was at risk, it was compared visually to the right wrist if the latter was not involved in the burn injury.

11. Ask the participant to move the affected joint into each range noted on the measurement chart. The researcher demonstrates the movement. Measure the range available with the goniometer and document the measured range. Ask the participant to move into range each movement to the most extent possible.
12. The participant returns the limb to the resting position.
13. The researcher moves the limb passively as far as the joint can move. The translator holds the position, the researcher measures the range available with a goniometer.
14. Documentation of the range of each movement is by audio, at the end of the participants interview audio file, and on a paper form.
15. The researcher returns the limb to the resting position.
16. Take a photo for the measurement Apps, the photo should include the affected joint and the joint above and below the joint measured, the face should not be included. The joint should be moved actively into the end range available for each movement measured at that joint.

APPENDIX 14: DMCH ETHICAL APPROVAL PILOT STUDY



ঢাকা মেডিকেল কলেজ
DHAKA MEDICAL COLLEGE
Dhaka, Bangladesh



Ref Memo No. MEU-DMC/ECC/2019/136

Date: 09/05/2019

Ethical Clearance Certificate

The Ethical Committee of Dhaka Medical College Approved the Following Protocol.

Title of the Research Work: "Identification of Risk Factors in Burn Contracture Formation".

Principal Investigator: RuthAnn Fanstone
PhD, BSc. (Hons) Physiotherapy student
Centre for Global Burn Injuries Policy and Research
Swansea University, UK

Supervisor: Dr. Mohammad Rabiul Karim Khan
Associate Prof. of Burn and Plastic Surgery
Dhaka Medical College, Dhaka.

Place of Study: Department of Burn and Plastic Surgery
Dhaka Medical College Hospital, Dhaka.

Duration: Two weeks.

[Redacted]
Prof. Dr. S.M. Shamsuzzaman
Head, Department of Microbiology &
Chairman,
Ethical Review Committee
Dhaka Medical College, Dhaka.

Dhaka Medical College, Dhaka-1000, Bangladesh. Phone: 880-2-55165088, Fax : 880-2-55165006
E-mail : principal@dmc.gov.bd, dmc_principal@yahoo.com, web: <http://www.dmc.gov.bd>

APPENDIX 15: FOCUS GROUP DISCUSSION GUIDE

The interviewer will:

- ✓ Introduce the research team and thank the participant for agreeing to take part in the FGD
- ✓ Go over the purpose of the FGD and answer any questions the participants may have
- ✓ Discuss confidentiality
- ✓ Advise the participant that they are free to leave the FGD at any time should they wish to do so
- ✓ Go through consent form, on an individual basis prior to the start of the group discussion

The following will be collected from each participant in advance of the FGD:

1. Number and location of contractures (measurements will not be taken)
2. When the burn injury occurred

FGD questions for discussion:

1. How participants refer to or describe their contracture (terminology)
2. Why and how participants think they have developed a contracture
3. As participants think about why and how they have developed a contracture they will be encouraged to consider this question in regards to i) time of injury to time of treatment ii) time of treatment iii) time after treatment
4. What participants expected regarding developing a contracture – were they aware that they may develop a contracture?
5. Do they think their contracture could have been prevented? Were participants aware that a contracture possibly could be prevented and what they think about this?
6. Can participants remember any advice they were given that could prevent or treat a contracture? If they can, what kind of advice were they given and were they able to follow it?
7. What if anything, do participants think made their contracture better or worse?

8. Can the participant remember how their contracture developed or progressed over time, when it started, when it got worse, when it got worse, did they have it when they left hospital or did it develop later?
9. Can the participants remember any therapy input to prevent or treat their contracture, if so, what can they remember?
10. Can they remember having pain during the burn healing and treatment and if so, how did the pain affect their ability to move and do things? What kind of pain threshold do the participants feel that they have?
11. Can the participants remember if they were offered skin grafting during the treatment and did they have skin grafting? What was their experience of this?
12. Can participant's think of anything else that they think had an impact on their contracture? Encourage participants to think broadly and not just to treatment, for example did their ability to read or their ability to pay impact the development of the contracture?
13. If this study is about preventing contractures what kind of things in the hospital care and speaking to people with contractures, do the participants think the researcher should be looking at or asking about?
14. What advice would the participants give for patients who are at risk of developing a contracture?

Actual Questions Discussed in FGD:

- Pointing to the contracture What do you call this?
- Have you heard of the word 'contracture' before?
- Why do you think you got a contracture (or did not get a contracture)?
- Can you think of anything that made the contracture better (clarify e.g., less stiff)?
- Can you think of anything that made the contracture worse?
- Do you think anything could have been done to prevent the contracture? If not, why not?
- Did you know when you had the burn that a contracture could develop?

APPENDIX 16: FINAL STUDY INTERVIEW GUIDE

After informing and consenting the participant, the interview will cover the following topics

About the participant

Age now and at the time of the injury

Where they live (rural or urban) and how far (hours and KMS) it is from the hospital (NIBPS)

- Employment and the employment of the head of the family e.g., the father or husband of the participant
- Education - level of completion and type (e.g., Bangla or English medium, Madrassa) of schooling (for participant and main carer), whether they can read and write
- Marital and family status – were they married at the time of burn, are they married now, the number children they have and the age of the children
- Who the main carer is now for the hospital admission (if admitted) and who it was at the time of the acute burn injury
- Past medical history – does the participant have any relevant past medical history

How the burn injury happened

- Date of burn
- How the burn happened and what the immediate (first aid) treatment was if any

Treatment seeking journey

If the participant did not seek any treatment, explore what they did do, why and what the outcome was

If the participant did seek treatment (informal or formal) explore for EACH treatment stop (annotated below for first treatment stop):

- Time between burn and arrival at first treatment stop
- When did they arrive at the first treatment stop
- Why did they choose to go to that treatment place
- What treatment did they have at that treatment stop
- When did they leave that treatment stop
- Why were they discharged from that treatment stop
- Who made the decision to leave the first treatment stop e.g., doctors or the participant left for other reasons

Definitive treatment stop (or hospital care) journey, often this will be NIBPS therefore annotated for NIBP below:

Date of admission to SHNIBPS

What is the reason why you are here (or visiting) the hospital today?

Have you been to this hospital before? Record how many times and why participant has been here before, detail on previous visits / admissions will be covered in the treatment and follow up sections below, not here

Clarify to the participant that you are asking the following (all sections below) about treatment that they had during their acute hospital or treatment stay:

What can you remember about the treatment you had for your burn?

Can you remember any advice you were given by anyone while in hospital?

Either explore what the participant offers in points above, or / and use the prompts below on the treatment areas to cover:

Emergency care

- Has there been an escharotomy or fasciotomy?
- Did you have an escharotomy or fasciotomy (the participant will either know these terms or the translator will describe the procedure, in the pilot no problem with understanding)
- The participant will know the terms HDU and ITU if they stayed there, explore if they needed any care in HDU and ITU and why, how long, did they have an inhalation injury

Infection

- Explore if the participant had an infection of their burn wounds (prompts = did you need special antibiotics for infection)

Skin grafting

Did you have any operations during your burn treatment?

If yes:

- What was the operation you had?
- Where did you have the operation?
- When did you have the operation?
- Did you have an operation to that area only once?
- How long did you not move (the joint grafted) after the operation?
- How long after the operation did you get discharged?
- Ask the above questions for each area grafted

If no:

- Were you offered an operation but decided not to have one?

If yes:

Why did you not have one?

Nutrition

- Did you lose much weight when you were in hospital?
- If yes, about how much weight did you lose? (participant is asked to describe in % e.g. I lost about 50% of my weight)
- Why do you think you lost weight?

Physiotherapist

- Have you seen a physiotherapist?
- How long after you arrived in hospital or after the burn injury did you have physiotherapy?
- How often do you see the physiotherapist?
- How many times in a week did you see the physiotherapist?
- How long does the physiotherapist spend with you?
- How long did the physiotherapist spend with you when he/she came?
- Did you do what the physiotherapist asked you to do, if not why not?

Splintage

Splint

- Did you have a splint

If yes:

- What kind of splint did you have?
- Where was the splint (what joint)?
- What position did the splint keep your (name joint) in?
- How long do you wear the splint for each day (24 hours)?
- When did you start wearing the splint?
- When did you stop wearing the splint?
- If there has been a lack of adherence explore the reasons why
- For those that did have this treatment - Explore the participants understanding on the rationale for the treatment / why it was needed / what it achieves

Positioning

- Were you given any advice about what position to be in when healing from the burn?

If yes:

- Ask the participant to demonstrate the position in lying, sitting and standing
- When you were in bed what position did you lie in
- How long did you stay in that position for at any one time?
- What position did you stay in in sitting (how long)
- What position did you stay in in standing
- Who (e.g., doctor) told you to stay in that position?
- How did they communicate to you about this
- When did you start the positioning?
- When you did the positioning how much movement could you get at (the affected joint) ask participant to demonstrate
- If there has been a lack of adherence explore the reasons why
- For those that did have this treatment - Explore the participants understanding on the rationale for the treatment / why it was needed / what it achieves

Exercise

- Have you been told to do any exercises

If yes:

- Who told you (e.g., doctor) to do the exercises?
- Did they just tell you how to do the exercises or did they show you how to do them?
- Have they helped you do them
- Did anyone spend any time helping you do the exercises?
- How many exercises did you do at any one time?
- How many times did you do the exercises (per day or week)
- When did you start doing the exercises (post admission or post burn)
- Did anyone move your joints for you to help you stretch or move or did you do the exercises and stretching yourself?
- If they received help – explore who the help was from and what they did
- When you did your exercises how much movement could you get at (the affected joint) ask participant to demonstrate
- If there has been a lack of adherence explore the reasons why
- For those that did have this treatment - Explore the participants understanding on the rationale for the treatment / why it was needed / what it achieves

Function

- When you were in hospital were you able to feed yourself?
- Walk to the toilet on your own?
- Brush your hair?
- How many hours during the day were you usually in bed? (24 hours)
- If there has been a lack of adherence explore the reasons why
- For those that did have this treatment - Explore the participants understanding on the rationale for the treatment / why it was needed / what it achieves

Pain Management

- Did you have pain when you were having your treatment?
- Can you tell me about your experience you had of the pain?
- How did the pain affect you?
- How was the pain at dressing change?
- How was the pain when you moved?
- Did you have pain medication?

If yes:

- Did you take pain medication every day?
- What pain medication did you take?
- How often did you take it?

- Any psychological help with the pain
- When you had pain that stopped you doing something why did the pain make you stop, what do you believe the pain was telling you?
- Level of pain (Visual Analogue Scale)
- Level of pain for dressing (Visual Analogue Scale)
- Level of pain for movement (Visual Analogue Scale)
- If there has been a lack of adherence explore the reasons why

Psychology

Have you seen a counsellor?

Discharge Status

Can you remember when you were discharged and why you were discharged?

Prompts

Explore date and reason for discharge

Wounds

- Were your wounds healed by the time you left hospital?

If yes:

- Confirm all areas were healed

If no:

- What was left to heal (ask participant to point/describe) the location and size of unhealed areas

Contractures

- Did you have full movement of all your joints by the time you left hospital?

If no:

- What joint had limited movement and ask the participant to demonstrate the movement they had available / the position the joint was in at the time of discharge
- Explore why they think their movement was limited on discharge

Post Hospital Care

What happened after you were discharged from hospital?

Prompts:

Were you given a follow up appointment to attend NIBPS again when you were discharged:

If no:

- Do you know why you did not get an appointment? Explore

If yes:

- When was the first appointment for after discharge?
- Did you attend for that appointment?
- Explore any reasons given for non-attendance

If yes:

- What were you advised on that appointment? Explore any treatment or advice given at follow up appointments

If no:

- Why did you not attend? Explore

If participant did not attend NIBPS for follow up:

- Where did you go for your dressings?
- Did you have any other follow up treatment elsewhere?
- Place of treatment on discharge
- Number of DMCH follow ups
- Treatment received in follow ups
- First advised readmission was required
- When you were home did you keep your joint positioned in any special way?
- Did you do any exercises at home?
- How long did it take before your wounds were fully healed? Explore for each joint involved
- After discharge (from this admission, after recon procedure) will you return for follow up?

Scar management

Pressure garments

- Did you have pressure garments?

If yes:

- When did you get the pressure garments
- How long per day did you wear the garments for (in 24 hours)
- When did you stop wearing the garments
- If there has been a lack of adherence explore the reasons why
- For those that did have this treatment - Explore the participants understanding on the rationale for the treatment / why it was needed / what it achieves

Moisturisation and scar massage

- Did you get advised to moisturise your scar
- Who told you have to moisturise your scar
- Did you do any scar massage
- Who told you
- Demonstrate scar massage
- When did you start scar massage?
- When did you stop scar massage?
- If there has been a lack of adherence explore the reasons why

- For those that did have this treatment - Explore the participants understanding on the rationale for the treatment / why it was needed / what it achieves

Cost

- How much does your family earn every month in Taka
- Are you able to tell me how much your care has cost so far?

Use prompts:

- Investigate how much the participant remembers paying for the following:
- Food and accommodation for relatives
- Food for patient
- Daily medications
- Special mediations
- Surgical supplies
- Dressings
- Splints
- Pressure garments
- Other
- Treatment not had due to cost
- Travel costs
- Other

Participant Opinion

- Who makes the decisions about your care – you, your family, the doctors
- Have you heard the word contracture before?
- If you have heard the word contracture before, who did you hear it from and when
- Why do you think you got this contracture
- Do you think anything could have stopped you getting this contracture?
- Did you know at the time of the burn or treatment that you could develop a contracture
- When did you first notice this contracture developing
- How did this contracture change over time?
- When did the contracture become fixed like it is now?

APPENDIX 17: FINAL STUDY PERSON DATA FORM (ODK FORMAT)

9/27/2019

Person_Form

Person_Form

This is a patient level form which has 11 sections and aims to extract quantitative data from reconstructive burn participants at a hospital in Bangladesh using a variety of sources- Interview, Notes, Observations

RESEARCH INFO

Today's Date

yyyy-mm-dd _____

Hospital Number

Where is the participant located in the hospital?

Study Number

Initials

Length of Interview (Minutes)

Name of Interviewer

MEDICAL NOTES

What was the participants age at the time of the burn injury

What is the participants' age now?

Gender

Male

Female

What is the reason for the patient being at DMCH?

Has the patient had previous reconstructive surgery?

- Yes
- No
- Don't know/remember

How many reconstructive procedures has the patient had?

When did the burn injury happen? (Years)

What caused the burn injury?

- Flame
- Hot Surface
- Hot liquid, steam or gas
- Electrical
- Chemical
- Friction
- Inhalation
- Cooling
- Radiation
- Other

Total Body Surface Area of Burn (TBSA) (to the nearest full percentage)

What is the depth of the burn overall?

- Superficial
- Partial
- Full Thickness
- Mixed

What is the participants past medical history?

- Nothing
- Mental Health
- Diabetes
- Pathology Reducing Joint Range of Movement
- Neurological deficit
- Other

Other past medical history?

Evidence of HO, amputation, neuropathy, nerve damage, inhalation injury

Was the burn injury intentional?

- Yes
- No
- Don't know/remember

How many days was it between the time of injury and the first treatment?**What place did this first treatment take place?**

- Traditional healer
- Family, friend or neighbour
- Village doctor
- Paramedics
- Primary health care
- Upazila health complex
- District hospital
- Medical College Hospital
- Non governmental organization
- Private institution
- NIBPS/DMCH
- Other

What treatment was received before definitive care?

- Dressings
- Antibiotics
- Fluid
- Pain Management
- Therapy
- Skin grafting
- Escharotomy
- Other

How many days was it between the injury and receiving definitive care?

Has the patient had an inhalation injury?

- Yes
- No
- Don't know/remember

Did the participant have any stay in ITU or HDU?

- Yes
- No
- Don't know/remember

How long was the ITU or HDU stay in days?

Has the participant had any escharotomy or fasciotomy?

- Yes
- No
- Don't know/remember

Has the participant had any skin grafts?

- Yes
- No
- Don't know/remember

How many skin grafts (operations) has the participant had?

Time from injury to first skin graft? (Weeks)

Time from injury to last skin graft? (Weeks)

Was there any graft failure?

- Yes
- No
- Don't know/remember

Did the participant refuse a skin graft?

- Yes
- No
- Don't know/remember

If so why?

Can the participant remember any pain medication (name, dose, route, frequency)

Did the participant keep their weight stable during the injury?

- Yes
- No
- Don't know/remember

Did the participant keep their weight stable during the injury?

Was there any infection?

- Yes
- No
- Don't know/remember

What was the date of discharge from definitive care? (Weeks)

Was participant discharged against medical advice?

- Yes
 No
 Don't know/remember

What was the reason for discharge from definitive care?

- Discharge against medical advice
 Medically discharged
 Lack of funds
 Went elsewhere for treatment
 Other

How many days after discharge was follow up scheduled?

Did the participant attend any follow up?

- Yes
 No
 Don't know/remember

How many days after discharge was follow up actually done?

How many follow up visits did the participant have?

When was the first sign of contracture?

PARTICIPANT DEMOGRAPHIC DATA**Where do you live?**

Is your home in a rural, urban or semi-urban area?

- Rural
- Urban
- Semi Urban

Distance from home to DMCH in km

Distance from home to DMCH in hours

Who was your main carer during acute treatment?

What is the participant's occupation?

Occupation of head of house (Breadwinner)

Was participant married at the time of the burn injury?

- Yes
- No
- Don't know/remember

Is the participant married now?

- Yes
- No
- Don't know/remember

How many children do you have?

Are you able to read? (participant)

- Yes
- No
- Don't know/remember

Are you able to write? (participant)

- Yes
 No
 Don't know/remember

What is your level of education? Recorded as text**Level of Education (participant)**

- None
 Primary Incomplete
 Primary complete
 Secondary incomplete
 Secondary Complete
 Honours
 Masters

Medium of Education

- English Medium
 Bangla Medium
 Madrasa

Level of Education (Carer)

- None
 Primary Incomplete
 Primary complete
 Secondary incomplete
 Secondary Complete
 Honours
 Masters

NATURE OF INJURY**When did the burn injury happen? (If exact or approximate date not recalled)**

When the burn happened what did you do immediately?

Did the participant have any first aid?

- Yes
- No
- Don't know/remember

Was the first aid effective?

- Yes
- No
- Don't know/remember

JOURNEY TO DEFINITIVE ACUTE CARE

Did you have any treatment for your burn injury?

- Yes
- No
- Don't know/remember

How many treatment stops did the participant make, before they got definitive care?

Where did participant received definitive care?

- Traditional healer
- Family, friend or neighbour
- Village doctor
- Paramedics
- Primary health care
- Upazila health complex
- District hospital
- Medical College Hospital
- Non governmental organization
- Private institution
- NIBPS/DMCH
- Other

What was the admission date to definitive care?

yyyy-mm-dd

What was the admission date to definitive care? (days)

What was the reason for any delay in treatment?

PHYSIO SEEN

On average how long did the participant spend in bed per 24 hours?

Has the participant seen a physiotherapist?

- Yes
- No
- Don't know/remember

When did the participant first see a physiotherapist? (Days post injury)

When did you first see a physiotherapist? (Days post admission)

Did the participant see the physiotherapist as an inpatient or outpatient?

- Inpatient
- Outpatient
- Both

How many times did the participant see a physiotherapist?

How long did the physiotherapist spend with the participant for each session? (Average time in minutes)

Was physiotherapy effective?

PYSIO TREATMENT

Did the participant have any splinting?

- Yes
- No
- Don't know/remember

Did the participant have any positioning?

- Yes
- No
- Don't know/remember

Did the participant have any exercise?

- Yes
- No
- Don't know/remember

Did the participant have any pressure?

- Yes
- No
- Don't know/remember

Did the participant have any scar massage?

- Yes
- No
- Don't know/remember

TREATMENT IN HOSPITAL (OTHER)

Did the participant move their (relevant parts) during the time they had the wounds?

- Yes
- No
- Don't know/remember

If no why not?

Did the participant move the (relevant part) fully (demonstrate Full Range Of Movement) during the time their wounds were healing?

- Yes
- No
- Don't know/remember

If no why not?

Did the participant see a counsellor?

Did the participant see a counsellor?

- Yes
- No
- Don't know/remember

If it was infected, why does the participant believe that it was infected?

DISCHARGE AND FOLLOW UP

Reason for no follow up?

- Financial
- Family stopped them from going
- Not offered
- Too far
- Did not understand the importance
- Other

Reason for no follow up?

What treatment was received at follow up?

- Dressings
- Pressure
- Splints
- Physiotherapy
- Nothing
- Other

What treatment was received at follow up?

What self treatment has the participant done, e.g. exercises

Did the participant know what to do on being discharged from hospital (advice, treatment and access)

TREATMENT COSTS

How much did you have to pay for your treatment costs for the acute care

How much did you have to pay for your treatment costs after discharge until now

Was there anything that you could not afford?

What were the 3 things that cost you the most during your whole care?

- Travel
- Operation
- Dressing Materials
- Dressing Procedure
- Pain Medication
- Antibiotics
- Other Medication
- Food
- Splints
- Therapist
- Other

Other top three costs if the options were not included above?

Where did you get money from to pay for your treatment?

Income Level per month (participant)

Income Level per month (Household)**PARTICIPANT OPINION****Have you heard of the word 'contracture' (using local medical term)?**

- Yes
- No
- Don't know/remember

When did the participant first hear the word contracture?

- Before Acute Care
- Acute Care
- After discharge
- Reconstructive Care
- Never
- Other

Other time points when participant first heard the word contracture.**Why do you think you have a contracture (what has caused the contracture)?****Do you think your contracture could be prevented?**

- Yes
- No
- Don't know/remember

Did you know when you had the burn that you may develop a contracture?

- Yes
- No
- Don't know/remember

Who makes the decisions about your care?

- Doctor
- Participant
- Family
- Other

Who are the others who make decisions about your care?

APPENDIX 18: FINAL STUDY JOINT DATA FORM (ODK FORMAT)

9/27/2019

Joint_Form

Joint Form

The UOA for this form is the joint. This is a child form that can be linked to the Recon Patient level form.

Today's Date

yyyy-mm-dd

Study No

Initials

Select all joints that are at risk of contracture

- Neck
- Right Shoulder
- Left Shoulder
- Right Elbow
- Left Elbow
- Right Wrist
- Left Wrist
- Right Hip
- Left Hip
- Right Knee
- Left Knee
- Right Ankle
- Left Ankle

Select all joints that have had reconstructive surgery

- Neck
- Right Shoulder
- Left Shoulder
- Right Elbow
- Left Elbow
- Right Wrist
- Left Wrist
- Right Hip
- Left Hip
- Right Knee
- Left Knee
- Right Ankle
- Left Ankle

Select all joints that are contracted

- Neck
- Right Shoulder
- Left Shoulder
- Right Elbow
- Left Elbow
- Right Wrist
- Left Wrist
- Right Hip
- Left Hip
- Right Knee
- Left Knee
- Right Ankle
- Left Ankle

NECK**Has it been grafted?**

- Yes
- No
- Don't know/remember

Could you move the joint fully at discharge?

- Yes
- No
- Don't know/remember

Could you move the joint fully at discharge?

When did you first notice the contracture? (Weeks)

How long has the contracture been as it is now?(Months)

Why do you think you DID NOT get a contracture?

Anything else

RIGHT SHOULDER

Has it been grafted?

- Yes
- No
- Don't know/remember

When was the first graft after the burn? (Weeks)

When was the last graft? (Weeks)

Was it re-grafted?

- Yes
- No
- Don't know/remember

Was the graft meshed? (Description)**Was the graft meshed?**

- Yes
- No
- Don't know/remember

Was the joint immobilised?

- Yes
- No
- Don't know/remember

How long was it immobilised for? (Weeks)

Was the joint splinted?

- Yes
- No
- Don't know/remember

How much was the splint?

When was the splint applied after the injury? (Weeks)

When did participant stop wearing the splint? (Weeks)

Describe the splint

Was splint effective?

- Yes
- No
- Don't know/remember

Describe adherence to splinting**Did the patient adhere to splinting?**

- Yes
- No
- Don't know/remember

Was the joint positioned?

- Yes
- No
- Don't know/remember

When did positioning start after the injury? (Weeks)

When did participant stop positioining? (Weeks)

Describe the positioning**Was positioning effective?**

- Yes
- No
- Don't know/remember

Describe adherence to positioning**Did the patient adhere to positioning?**

- Yes
- No
- Don't know/remember

Did the joint get pressure?

- Yes
- No
- Don't know/remember

When did pressure start after the injury? (Weeks)

When did participant stop pressure? (Weeks)

Describe the pressure

How much did the pressure garment cost?

Was pressure effective?

- Yes
- No
- Don't know/remember

Describe adherence to pressure

Did the patient adhere to pressure?

- Yes
- No
- Don't know/remember

During acute care could you brush your hair independently?

- Yes
- No
- Don't know/remember

During acute care could you feed yourself independently?

- Yes
- No
- Don't know/remember

When did the skin over the joint heal? (Weeks)

9/27/2019

Joint_Form

Did the wound get infected?

- Yes
- No
- Don't know/remember

Could you move the joint fully at discharge?

- Yes
- No
- Don't know/remember

Could you move the joint fully at discharge?

When did you first notice the contracture? (Weeks)

How long has the contracture been as it is now?(Months)

Why do you think you DID NOT get a contracture?

Anything else

LEFT SHOULDER

Has it been grafted?

- Yes
- No
- Don't know/remember

When was the first graft after the burn? (Weeks)

When was the last graft? (Weeks)

APPENDIX 19: RESEARCH CHECK LIST FINAL STUDY

	1	2	3
DATE			
Name			
Location			
PARTICIPANT DEMOGRAPHIC DATA			
CAN YOU TELL ME A LITTLE ABOUT YOU			
What is the participants' age now?			
Gender			
Where do you live?			
Is your home in a rural, urban or semi-urban area?			
Distance from home to DMCH in km			
Distance from home to DMCH in hours			
Who was your main carer during acute treatment?			
What is the participant's occupation?			
Occupation of head of house (Breadwinner)			
Was participant married at the time of the burn injury?			
Is the participant married now?			
How many children do you have?			
Are you able to read? (participant)			
Are you able to write? (participant)			
Are you able to read? (Carer)			
Are you able to write? (Carer)			
What is your level of education? Recorded as text			
Level of Education (participant)			
Medium of Education			
Level of Education (Carer)			
What is the reason for the patient being at DMCH?			
NATURE OF INJURY			
CAN YOU TELL ME WHY YOU ARE IN HOSPITAL TODAY?			
CAN YOU TELL ME WHEN THE BURN INJURY HAPPENED AND HOW IT HAPPENED?			
CAN YOU TELL ME ABOUT ANY TREATMENT THAT YOU REMEMBER HAVING FOR YOUR INJURY?			
When did the burn injury happen?			
When did the burn injury happen? (If exact or approximate date not recalled)			
What caused the burn injury?			
When the burn happened what did you do immediately?			
Did the participant have any first aid?			

Was the first aid effective?		
Total Body Surface Area of Burn (TBSA) (to the nearest full percentage)		
TBSA CHART		
What is the depth of the burn overall?		
Was the burn injury intentional?		
What is the participants past medical history?		
Other past medical history?		
Evidence of HO, amputation, neuropathy, nerve damage, inhalation injury		
JOURNEY TO DEFINITIVE ACUTE CARE		
Did you have any treatment for your burn injury?		
How many days was it between the time of injury and the first treatment?		
What place did this first treatment take place?		
What treatment was received before definitive care?		
How many treatment stops did the participant make, before they got definitive care?		
How many days was it between the injury and receiving definitive care?		
Where did participant receive definitive care?		
What was the length of stay at the place where participant had definitive care? (days)		
What was the reason for any delay in treatment?		
TREATMENT IN HOSPITAL (EMERGENCY CARE)		
Did the participant have any stay in ITU or HDU?		
How long was the ITU or HDU stay in days?		
Has the patient had an inhalation injury?		
Has the participant had any escharotomy or fasciotomy?		
TREATMENT IN HOSPITAL (SKIN GRAFTING)		
Has the participant had any skin grafts?		
How many skin grafts has the participant had?		
Time from injury to first skin graft? (Weeks)		
Time from injury to last skin graft? (Weeks)		
Was there any graft failure?		
Did the participant refuse a skin graft?		
If so, why?		
PHYSIO SEEN		
On average how long did the participant spend in bed per 24 hours?		

Has the participant seen a physiotherapist?			
When did the participant first see a physiotherapist? (Days post injury)			
When did you first see a physiotherapist? (Days post admission)			
Did the participant see the physiotherapist as an inpatient or outpatient?			
How many times did the participant see a physiotherapist?			
How long did the physiotherapist spend with the participant for each session? (Average time in minutes)			
Was physiotherapy effective?			
Was physiotherapy effective?			
PHYSIO TREATMENT			
Did the participant have any splinting?			
Did the participant have any positioning?			
Did the participant have any exercise?			
Did the participant have any pressure?			
Did the participant have any scar massage?			
JOINT LEVEL QUESTIONS FOR A AT RISK OR CONTRACTURED JOINT			
Has this joint had a previous reconstruction?			
Has it been grafted?			
When was the first graft after the burn? (Weeks)			
When was the last graft? (Weeks)			
Was it re-grafted?			
Was the joint immobilised?			
How long was it immobilised for? (Weeks)			
Was the joint splinted?			
When was the splint applied after the injury? (Weeks)			
When did participant stop wearing the splint? (Weeks)			
Describe the splint			
Was splint effective?			
Describe adherence to splinting			
Did the patient adhere to splinting?			
Was the joint positioned?			
When did positioning start after the injury? (Weeks)			
When did participant stop positioning? (Weeks)			
Describe the positioning			
Was positioning effective?			
Describe adherence to positioning			
Did the patient adhere to positioning?			
Did the joint get pressure?			
When did pressure start after the injury? (Weeks)			

When did participant stop pressure? (Weeks)			
Describe the pressure			
Was pressure effective?			
Describe adherence to pressure			
Did the patient adhere to pressure?			
During acute care could you brush your hair independently?			
During acute care could you feed yourself independently?			
During acute care could you mobilise?			
When did the skin over the joint heal? (Weeks)			
Did the wound get infected?			
Could you move the joint fully at discharge?			
When did you first notice the contracture? (Weeks)			
How long has the contracture been as it is now?(Months)			
PARTICIPANT OPINION			
Have you heard of the word 'contracture' (using local medical term)?			
When did the participant first hear the word contracture?			
Other time points when participant first heard the word contracture.			
Why do you think you have a contracture (what has caused the contracture)?			
Do you think your contracture could be prevented?			
Did you know when you had the burn that you may develop a contracture?			
Who makes the decisions about your care?			
Who are the others who make decisions about your care?			
When was the first sign of contracture?			
RATIONALE FOR EFFECTIVENESS AND ADHERENCE			
Splinting			
Can you describe the splint to me			
Where did it go (over which joint, over which aspect, how long, how wide)			
What was it made of (was it hard, soft)			
Where did the splint come from			
Was it bespoke, made by an orthotist, physio			
When did you get the splint? (how long post burn, how long post admission)			
Was it bespoke, made by an orthotist, physio			
How was the splint secured?			
What position did your splint keep your e.g., knee, elbow in (demonstrate)			
Was the fit of the splint changed over time			
When did you stop wearing the splint?			

Why did you not wear the splint?		
Pressure		
Can you describe the pressure garment to me		
What area was covered by the pressure garment		
When did you start wearing the pressure garment		
Where did the pressure garment come from		
How many hours a day did you wear the pressure garment		
Did you wear the pressure garment every day		
How many pressure garments did you have		
How many times did you get a new pressure garment		
Why did you not wear the pressure garment		
Positioning		
What position did you sleep in		
What position did you sit in		
Who told you to be in that position		
Did they help you get into that position or did they just tell you		
How long did you spend in that position		
Did anything stop your positioning		
Exercise		
What exercises did you do		
Who told you to do them		
Did they help you do them or demonstrate them or just tell you to do them		
Did you achieve full movement of the joint		
Did anyone help stretch your joints as far as possible, or did you only move your joints		
How many times a day did you do the exercises, did you do them every day		
When did you start to do the exercises		
When did you stop the exercises		
Did anything stop you doing the exercises		
Scar massage		
Can you show me how you did the massage		
When did you start to do the massage		
How many times a day did you do the massage		
Who did the massage		
When did you stop the massage		

APPENDIX 20: DATA COLLECTED FROM MEDICAL NOTES

1. Hospital number
2. Participant age now
3. Participant age at time of burn
4. Address (District only)
5. Date of burn
6. History of burn
7. Admission date (this admission and any previous)
8. Past medical history
9. Cause of burn
10. Any documentary evidence of infection
11. Any documentary evidence of ITU or HDU stay
12. Burn chart and TBSA of burn (take photo)
13. Depth of burn
14. Any documentary evidence of participant's weight
15. Any documentary evidence of an inhalation injury
16. Any documentary evidence of an amputation
17. Any documentary evidence of neuropathy
18. Dates of any previous NIBPS admissions
19. Dates of any previous NIBPS discharges
20. Any documentary evidence of escharotomy or fasciotomy
21. Any dates and locations of skin grafting surgery
22. Any documentary evidence of previous pain medication and dose
23. Any documentary evidence of pressure garments either advised or administered
24. Any documentary evidence of advice to scar massage
25. Any documentary evidence of wound healing status or graft take
26. Any documentary evidence of contracture development
27. Dates and any details on follow up appointments to NIBPS
28. Any documentary evidence of previous treatment given at follow up visits

APPENDIX 21: PARTICIPANT INFORMATION FINAL STUDY

Introduce yourself (the translator) – inform the participant that we are finding out if they are interested to be involved in some research, this is not about treatment.

Explain the participant will gain nothing from taking part in this study other than helping us and hopefully future burn patients.

Before you decide if you want to be involved, we want to give you all the necessary information about the study, please ask us any questions that you have

Introduce RuthAnn – Physiotherapist specializing in burns from UK (they do not understand Swansea or Wales) who has worked in this hospital many times before, she is doing her PhD research. She is working with a translator because she cannot speak Bangla.

We are asking you if you would like to be involved in this study because you have come to this hospital because of this skin tightening (point to the contracture). This study is about how we may be able to improve this skin tightening after a burn (point to the participants contracture). To see if you would be willing to be part of the study, I would like to tell you a bit about the study and what it will involve. Will this be ok? It will take about 10 minutes to explain the study to you and then for the questions we have to ask you will take about 30 minutes.

You do not have to be involved in this study; it is totally your choice. We are happy if you would like to be involved but we are equally as happy if you feel you do not want to be involved, and you don't have to explain to us why you don't want to be involved. Please say no if you are not sure that you want to be involved or if it is inconvenient for you to be involved. If you don't want to be involved no one other than us will know about this decision. If you do take part in the study then it will not affect your care in anyway and we will not share the information you give us with anyone else in this hospital.

No harm will come to you by being involved in this study. You will be helping us understand ways to better care for burn patients.

If you do agree to be involved this will happen:

We will ask you some questions to check you understand the information I am giving you now, then you can sign that you understand the information – either with a thumb print or a signature (show the consent form).

The research team will look at your medical notes and collect some information from them, this will take about ten minutes.

Once you agree to be involved we want to give you time to think about your involvement, to make sure you are happy to be involved. We will ask you to leave

the room and return in 20 minutes to indicate that you are happy for us to ask you the questions (outpatients). We will return to see you in 2 hours from now or tomorrow, whatever you prefer (inpatients).

Then we will sit with you and ask you some questions about you, how your burn happened and what kind of treatment you had. This will take about 30 minutes. It is not a problem if you do not know the answers to any questions. We just want to hear and learn from your experiences of what you remember. Your chosen relative can help you with anything you are unable to remember.

We will record the questions we ask you and the answers that you give, making a file on this phone. The file will be kept secure and confidential.

After we have finished asking the questions, we will examine your joints and take some measurements and photos. This will take about 10 minutes. This involves you making the movement (demonstrate), and then we will help you with the movement (demonstrate how we do a passive movement) and then we will measure the angle with this instrument (show). We will also take some photos of your joint; we will not include your face. After this we do not need any more involvement or help from you. We will look after all the information and any photos from you, they will be kept confidential and secure, no one will see this information other than the research team which is RuthAnn and the small research team at her University. The findings of the study will be published, this includes the information that you give us but no one will know it is information from you.

If you have any questions, please ask us and if at any point during the questions you want to stop and do not want to carry on that is no problem. How you feel is more important to us than this study.

Even once we have started the interview and you want to stop and leave that is fine, even at the end interview you have up until we leave you if you decide you don't want us to use the information and we will not include it in the study

I wish you well

At the end of the interview / contracture measurement:

Please thank the participant very much

Tell the participant that being involved in the study will help other burn patients in the future

Ask the participant how they felt about the questions and if it was difficult for them
Ask the participant if they would like to talk to anyone about and explain why you are giving them the contact card of the psychologist

Ask if they have any questions

Wish them well

APPENDIX 22: PARTICIPANT CONSENT FORM FINAL STUDY (BANGLA)

বার্ন কঞ্চাকচার গঠনের জন্য ঝুঁকি সনাত্তকরণ

প্রিপিপাল গবেষক : রংধ্যান ফ্যানস্টেন, পিএইচডি থার্থী, সেন্টার ফর গ্রোবাল বার্ন ইনজুরি পলিসি অ্যান্ড রিসার্চ,
সোয়ানসি ইউনিভার্সিটি, সোয়ানসি, এসএ ২৪ পিপি, ইউ কে ওয়েলস।

তারিখ :
আমি নিশ্চিত করছি যে আমাকে এই গবেষণা সম্পর্কে ব্যাখ্যা করা হয়েছে এবং এই গবেষণায় আমার সংশ্লিষ্টতা সম্পর্কে জানানো হয়েছে। আমি স্বেচ্ছায় এই গবেষণায় জড়িত হয়েছি এবং আমি জানি যে, যে কোন সময়, কোন কারণ ছাড়া আমার অংশগ্রহণটি আমি প্রত্যাহার করে নিতে পারি এবং এতে করে আমার চিকিৎসার কোন নেতৃত্বাচক প্রভাব পড়বে না।
আমি ঝুঁকি যে, এই গবেষণায় আমার ভূমিকা কি এবং আমার সকল প্রশ্নের উত্তর সন্তুষ্টির সহিত দেওয়া হয়েছে।
আমাকে জানানো হয়েছে যে, আমি যে তথ্যগুলো প্রদান করেছি সেগুলো নিরাপদে ও গোপনে রাখা হবে এবং আমার দেয়া প্রদত্ত তথ্য শুধু মাত্র বেলামে এই গবেষণায় ব্যাবহার করা হবে।
গবেষণার প্রয়োজনে আমার কথা আডিও রেকর্ড করা যেতে পারে।
গবেষক গবেষণার প্রয়োজনে আমার মেডিক্যাল নোটগুলি দেখতে এবং এর থেকে প্রয়োজনীয় তথ্য সংগ্রহ করতে পারেন।
আমার বার্নের ফটো তোলা ও তা গবেষণার কাজে ব্যাবহার করার জন্য আমি অনুমতি দিচ্ছি। কিন্তু আমার বার্নের ছবি গবেষণা প্রতিবেদনে প্রকাশ করা হলে আমার পরিচয় গোপন রেখে তা করা হবে। যদিও আমি জানি যে আমার ছবি প্রতিবেদনে প্রকাশের সম্ভাবনা কম।
প্রয়োজন হলে গবেষক আমার বার্নে ক্ষতিগ্রস্ত জোড়ের পরিসর করতে পারবেন এবং কীভাবে এই পরিমাপ করা হবে তা আমাকে ব্যাখ্যা করা হয়েছে।

এই গবেষণায় আপনার অংশগ্রহণের জন্য আপনাকে ধন্যবাদ। আপনার সাহায্য খুব প্রশংসনীয়।

অংশগ্রহণকারীর নাম

স্বাক্ষর

তারিখ

গবেষকের নাম

স্বাক্ষর

তারিখ

প্রিপিপ্যাল গবেষকের নাম

স্বাক্ষর

তারিখ

APPENDIX 23: CONSENT FORM IN ENGLISH

Identification of the Risk Factors for Burn Contracture Formation

Principal Researcher – RuthAnn Fanstone, PhD Candidate, Centre for Global Burn Injury Policy and Research, Swansea University, Swansea, SA2 8PP, Wales

	Participant initial
I (the participant) confirm that I have read and understand the information sheet for the above study (dated) which is attached to this form.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons.	
I understand what my role will be in this research, and all my questions have been answered to my satisfaction.	
I understand that I am free to ask any questions at any time before and during the study.	
I have been informed that the information I provide will be safeguarded/ kept safely.	
I am happy for the information I provide to be used (anonymously) in academic papers and other formal research outputs.	
I am willing for my information to be audio recorded.	
I am willing for the researcher to look at my medical notes and collect the necessary data from them	
I am willing for my joint to be photographed by the researcher and I understand that only my joint will appear in the photograph, my face will not be included	
I am willing for my joints to be measured by the researcher if required, I understand how this will be done	
I have been provided with a copy of the Participant Information Sheet.	
I agree to the researchers using my personal data in the way that is described in the Participant Information Sheet.	

Thank you for your participation in this study. Your help is very much appreciated.

Print name of participant

Signature

Date

Print name of researcher

Signature

Date

This study is being conducted by Swansea University, College of Human and Health Science. When complete: Original copy for the participant, one copy to be retained by researcher

APPENDIX 24: OPERATIONALISATION OF RISK FACTORS AND DATA SOURCES

Risk Factor	Unit of Analysis	Operationalisation
Demographic		
Residence Location	Person	Urban, semi-urban, rural - defined by the participant/interpreter Region – participant reports the region in which they live (if the place of injury was different from the place of residence, place of injury is selected)
Literacy	Person	Literate – if the participant reports he/she is able to read and write
Level of education	Person	Participant report Primary – incomplete / complete (class 1-5) Secondary – incomplete/complete (class 6-8) Tertiary – incomplete/complete (honours and masters or above) Incomplete = participant started but did not complete that level of education
Occupation	Person	Participant reports his/her current occupation
Monthly income of the household	Person	Participant reports monthly income in BDT for their whole household (income of all wage earners in the household)
Distance from home to DMCH (km)	Person	Kms (single journey) from participant's current home to DMCH/SHNIBPS
Time from home to DMCH (hrs)	Person	Hours (single journey) from participant's current home to DMCH/SHNIBPS
Burn Factors		
Age at time of burn	Person	Age (in years) of the participant at the time of the burn injury from participant report +/- medical records
Time since burn	Person	Time (in years) from injury to date of data collection from participant report +/- medical records
Cause of burn	Person	Participant report +/- medical record of source and type of burn injury
Total Body Surface Area (TBSA) burn	Person	Reported TBSA of burn (based on rule of nines) from participant report +/- medical records
Total Body Surface Area (TBSA) burn by category	Person	Categorisation of TBSA burn (>15%, 15-30 %, >30% TBSA). If no TBSA data reported, researcher estimated TBSA from body chart sketch
Depth of burn	Person/Joint	Depth of burn, categories generated from patient report / medical documentation
First aid	Person	Any immediate action taken toward the burned area in response to sustaining the burn injury

Appropriate first aid	Person	Immediate application of water, without application of any additional substance to the burned area + immediate presentation to any level of biomedical care
Inhalation injury	Person	Medical documentation/discussion between interpreter (medical doctor) and participant re history of burn and whether patient reported common signs/symptoms of inhalation injury or had any ITU stay.
Infection	Person/Joint	Medical documentation of infective organism on laboratory culture. Patient reports doctor informed them of having an infection or had to buy antibiotics
Escharotomy	Person	Any visible marks (linear line in the expected areas for escharotomy) or medical record/patient report of escharotomy
Neuropathy	Person	Medical documentation of neuropathy +/- patient reported symptoms of neuropathy, + researcher observation during joint assessment
Heterotopic Ossification (HO)	Person	Medical documentation of HO or researcher observation during joint assessment
Amputation	Person	Amputation observed, participant confirms as result of burn
Time to heal	Person	Medical record/participant report of time (weeks) taken for wounds over/near each major joint to have healed with no requirement for dressings. Longest healing time used to determine time to healing.
Time to heal	Joint	Medical record/participant report of time taken for wounds over/near each joint at risk to have healed with no requirement for dressings (weeks)
Past Medical History	Person	Participant report/medical record/researcher observation of other physical or psychological pathology. Also asked if joint at risk had any limitation of movement prior to burn; researcher observed any other visible pathology to joint apart from burn injury
Intentional burn	Person	Determined from the history of the burn injury from participant report +/- medical record
Reconstructed joint	Person/Joint	Participant report +/- medical record of any joint previously having non-acute surgery to release reported or current contracture
Joint at Risk	Person/Joint	Joint having any observable significant scarring which met or crossed a joint line and was believed likely to result in a contracture
Contracture	Person/Joint	Any measured loss of passive ROM based on the mean of 3 passive movements made following 3 active movements of the joint(s) at risk
Healthcare Access		
Type of care	Person	Patient report and medical documentation defining place of care as government facility/private/overseas

No treatment	Person	Participant report/medical record did not receive acute care in any formal healthcare facility (of any level) for > 48 hours
Level of healthcare	Person	Participant report and medical documentation of healthcare facilities attended
Place of first care	Person	Participant report/medical record of level of healthcare facility attended for first care following burn injury
Treatment given before definitive care	Person	Participant report +/- medical documentation detailing treatment given before reaching definitive care. Later categorised as: No treatment – no intervention given Basic – dressings, IV, medication Basic+ - any additional input to basic care such as grafting, splinting, physiotherapy
Definitive care	Person	Patient report/medical record of level of health care facility where the patient had the majority of burn care, and which was the last place of inpatient care
Time to first care	Person	Patient report/medical record of time (in days) for patient to reach place of first care following burn
Time to definitive care	Person	Patient report/medical record of time (in days) for the patient to reach definitive care following the burn injury
Specialist care	Person	Tertiary level hospital providing specialist burn care including ITU, skin grafting and physiotherapy.
Length of stay (LOS)	Person	Patient report/medical record of time in any level of facility between admission and discharge (weeks); cumulative total if patient had care > 24 hours in any healthcare facility
Intensive Therapy Unit (ITU) treatment	Person	Patient report/medical record of any stay in an ICU/ITU unit
ITU length of stay	Person	Patient report/medical record of time (days) spent in an ICU/ITU unit
Discharge against medical advice	Person	Patient report/medical record of participant decision to leave hospital against medical advice of medical team OR participant was referred to a higher level of facility but decided to return home
Follow up received	Person	Patient report/medical record of returning to any healthcare facility for review within 3 months of discharge
Time to first follow up	Person	Patient report/medical record of time (days) from discharge to follow up
Number of follow ups	Person	Patient report/medical record of no of follow-up visits attended from discharge to date of data collection
Healthcare Access (cont)		
Cost of care	Person	Participant report of total funds spent on care from time of injury to data collection
Medical/Surgical Treatment		

Skin graft	Person and Joint	Patient report/medical record of skin graft operation OR patient reports a history of skin graft (and can describe that skin was taken from one location and put over an area of burn) and researcher observed a scar consistent with skin graft
Type of skin graft	Person and joint	Medical record or researcher observation of graft site (meshed, fenestrated, or sheet graft)
Time to first skin graft	Person	Patient report/medical record of time (weeks) from injury to first skin graft of any joint at risk
	Joint	Patient report/medical record of time (weeks) from injury to first skin graft of specific joint at risk
Time to last skin graft	Person	Patient report/medical record of time (weeks) from injury to last skin graft of any joint at risk
	Joint	Patient report/medical record of time (weeks) from injury to last skin graft of specific joint at risk
Number of skin grafts	Person	Patient report/medical record of total number of skin grafts to all joints at risk
Graft failure	Joint	Patient report/medical record of graft failure; patient was asked if the same location required a skin graft more than once
Refusal of skin graft	Person and Joint	Patient report/medical record of refusal of skin graft for a first or subsequent graft. If patient required but was not offered a skin graft, this was not included as refusal of skin graft
Pain management	Person	Patient report/medical record of their experience of pain +/- list of type, frequency, route of administration and effectiveness of any pain medication.
Nutritional status	Person	Patient report of pre-burn weight and weight at time of wound healing, and if they lost weight during recovery from acute burn injury
Rehabilitative Treatment		
Rehabilitative Treatment		
Seen by physiotherapy		Patient report/medical record of being seen by a qualified physiotherapist (diploma or BSc). Therapy interventions advised without assessment by a qualified physiotherapist were defined as no physiotherapy input
Time to physiotherapy		Patient report/medical record of time (weeks) to first physiotherapy input post-injury
Place of physiotherapy		Patient report/medical record of nature of physiotherapy (inpatient/outpatient/both)
Rehabilitative Treatment (cont)		
Times seen by physiotherapy		Patient report of no of contacts with physiotherapist from burn injury until date of data collection
Physiotherapy time		Patient report of average time (minutes) spent with physiotherapist per session

Exercised	Person	Patient report of any instruction received (not only from physiotherapist) to institute active/passive movement of joints, whether followed or not
Positioned	Person	Patient report of any instruction received (not only from physiotherapist) on anti-contracture positioning of any joint at risk, whether followed or not
	Joint	Patient report of any instruction received (not only from physiotherapist) on anti-contracture positioning of specific joint at risk, whether followed or not
Effective positioning	Person and Joint	Effectiveness of positioning determined by researcher based on: <ul style="list-style-type: none"> • position (demonstrated/explained by patient for each joint at risk) • time after burn at which positioning was initiated and stopped • time spent in required position • whether patient understood importance of the positioning
Splinted	Person	Patient report of any rigid material used to fix position of any joint at risk
	Joint	Patient report of any rigid material used to fix position of specific joint at risk
Effective splinting	Person and joint	Effectiveness of splinting determined by researcher based on: <ul style="list-style-type: none"> • patient description of the splint • time splint was initiated and removed • position in which joint held • whether patient understood importance of splinting
Pressure Garment Therapy (PGT)	Person	Patient report of being given a commercially provided pressure garment for any joint at risk (not tubigrip or compression bandages)
Pressure	Joint	Patient report of being given a commercially provided pressure garment for the specific joint at risk
Effective pressure	Person	Effectiveness of PGT decided by the researcher based on: <ul style="list-style-type: none"> • patient description of pressure garment(s) • time of initiation and duration of PGT (weeks) • time garment worn/day (hours) • whether PGT was reviewed by provider of PGT during period the garment was worn
Scar massage	Person and Joint	Patient report/medical record of application of moisturisation to scars
Immobilised	Person	Patient report/medical record of any joint at risk being fixed in position for any time for any reason other than splinting e.g., post-skin grafting, by traction or by instruction. (Plaster of Paris (POP) back-slabs defined as splints, POP cylinders defined as immobilisation)

	Joint	Patient report/medical record of specific joint at risk being fixed in position for any time for any reason other than splinting e.g., post-skin grafting, by traction or by instruction. (Plaster of Paris (POP) back-slabs defined as splints, POP cylinders defined as immobilisation)
Psychosocial support	Person	Patient report/medical record of psychosocial support at any time after burn injury from someone with training in psychological care (not a friend/relative)
Patient Opinion		
Knowledge of the word contracture	Person	Whether the English word 'contracture' had been heard by patient at any point since burn injury
Awareness of contracture as an outcome of burn injury	Person	Whether patient knew during acute care phase that a contracture could result from burn injury

APPENDIX 25: ETHICAL APPROVAL FINAL STUDY

Ethics application RuthAnn Fanstone 230719b 0 5 ↻ +

 Smith A.M. on behalf of CHHS Ethics
Fri 16/08/2019 00:01

To: FANSTONE R. ([REDACTED]
Cc: Potokar T.S.; CHHS Ethics; Bird R.

Dear RuthAnn,

Ethics application - Stage 2 - 230719b

Many thanks for your e-mail and amended application. Formal approval for your study is now granted. Please forward me the relevant Ministry approval when received. I wish you well with your research.

Best wishes,

[REDACTED]

Angela Smith
Senior Lecturer in Health Care Law and Ethics | Uwch Ddarlithydd mewn Cyfraith Gofal Iechyd a Moeseg

Chair, CHHS Ethics Committee
<https://www.swansea.ac.uk/humanandhealthsciences/research-at-the-college-of-human-and-health/research-ethics-committee/>

College of Human and Health Sciences | Coleg y Gwyddorau Dynol ac Iechyd
Singleton Park | Parc Singleton
Swansea | Abertawe
Wales | Cymru
SA2 8PP

Room 700 Vivian Tower| Ystafell 702, Vivian
Swansea University | Prifysgol Abertawe
Phone | Ffôn Ext. 01792 513343

APPENDIX 26: LETTER OF PERMISSION FROM SHNIBPS



SHEIKH HASINA NATIONAL INSTITUTE OF BURN AND PLASTIC SURGERY

Gyantaposh Dr. Muhammad Shahidullah Road, Dhaka-1000.



DIRECTOR

Date.....

11th September 2019

TO WHOM IT MAY CONCERN

The Sheikh Hasina National Institute Of Burn and Plastic Surgery is pleased to welcome and extend support to RuthAnn Fanstone, PhD Student from Swansea University United Kingdom, to complete her final data collection for the PhD 'Identification of Risk Factors in Burn Contracture Formation'. We look forward to working on this study with RuthAnn and will provide local help for purposes of data collection and translation. We believe this study is important and relevant for the improvement of burn care in Bangladesh. We expect RuthAnn's visit to be of 4 weeks duration in October 2019.

With Kind Regards



Professor Dr. Md. Abul Kalam
Director and Professor
Sheikh Hasina National Institute of Burn and Plastic Surgery
Dhaka
Bangladesh
Email : pdnibps@gmail.com sheikhhasina@hospi.dgbs.gov.bd kalammishu@yahoo.com
Mobile : +880 1730 44 30 40

APPENDIX 27: MINISTRY OF HEALTH APPROVAL (BANGLA ORIGINAL)

গণপ্রজাতন্ত্রী বাংলাদেশ সরকার
 স্বাস্থ্য ও পরিবার কল্যাণ মন্ত্রণালয়
 স্বাস্থ্য সেবা বিভাগ
 সরকারি স্বাস্থ্য ব্যবস্থাপনা-১
 বাংলাদেশ সচিবালয়, ঢাকা

তারিখ: ১৩.১০.২০১৯ ইং

নং-৪৫.০০.০০০০.১৫৫.১১.০১৬.১৭-

বিষয়: **বিদেশী (ব্রিটিশ) ফিজিওথেরাপিস্ট চিকিৎসককে বাংলাদেশে আগমন ও অবস্থানের অনুমতি প্রদান।**

সুব্রহ্মণ্য শেখ হাসিনা ন্যাশনাল ইনসিটিউট অব বার্থ ও প্লাস্টিক সার্জারী স্লাপন প্রকল্প, ঢাকা এর ০৬-১০-২০১৯ তারিখের ৩১৯ সংখ্যক পত্র।

উপর্যুক্ত বিষয়ে ও সুন্দরোভ্য সারকরের পরিপ্রেক্ষিতে বিদেশী (ব্রিটিশ) ফিজিওথেরাপিস্ট চিকিৎসককে ছকে বর্ণিত প্রতিষ্ঠান ও সেবাদে একাডেমিক সফরের লক্ষ্যে বাংলাদেশে আগমন ও অবস্থানে নিম্নোক্ত শর্ত সাপেক্ষে নির্দেশনামে অনুমতি প্রদান করা হলোঃ

ক্রম নং	চিকিৎসকের নাম ও পদবী	জাতীয়তা	আগমনের উদ্দেশ্য	সেবাদানের প্রতিষ্ঠান	অনুমোদিত সময়কাল
১	RuthAnn Fanstone	ব্রিটিশ	একাডেমিক সফর	শেখ হাসিনা জাতীয় বার্থ ও প্লাস্টিক সার্জারী ইনসিটিউট, ঢাকা	১২-১০-২০১৯ তারিখ হতে ৬ (ছয়) সপ্তাহ

শর্তসমূহ:

- (ক) বিএমডিসি হতে অস্থায়ী রেজিস্ট্রেশন গ্রহণ করে ৭ (সাত) দিনের মধ্যে স্বাস্থ্য সেবা বিভাগকে অবহিত করতে হবে;
- (খ) বাংলাদেশে আগমন ও অবস্থানে বাংলাদেশ সরকারের কোন আর্থিক সংশ্লেষ থাকবে না;
- (গ) বাংলাদেশে আগমন ও অবস্থানের বিষয়টি স্বরাষ্ট্র মন্ত্রণালয়, পরবর্তী স্বরাষ্ট্র মন্ত্রণালয় এবং স্বাস্থ্য ও পরিবার কল্যাণ মন্ত্রণালয়কে অবহিত করতে হবে;
- (ঘ) উল্লিখিত তারিখে বাংলাদেশে অবস্থান করে শুধুমাত্র সংশ্লিষ্ট প্রতিষ্ঠানে চিকিৎসা/প্রশিক্ষণ প্রদান করতে পারবেন এবং কোনওভাবেই প্রাইভেট প্রাকটিস বা অন্য কোন প্রাতিষ্ঠানে কাজ করতে পারবেন না;
- (ঙ) বর্ণিত চিকিৎসকের সফর শেষ হওয়ার এক সপ্তাহের মধ্যে আবেদনকারী প্রতিষ্ঠান কর্তৃক একটি স্বয়ংসম্পূর্ণ প্রতিবেদন এ বিভাগে দাখিল করতে হবে; এবং
- (চ) নির্ধারিত সময়ের পর উল্লিখিত চিকিৎসকদের দেশ ত্যাগ সংক্রান্ত প্রতিবেদন এ বিভাগকে অবহিত করতে হবে।

(মো: আবু রায়হান মির্জা)

উপসচিব

ফোনঃ ৯৫৫৬৯৮৯

ডাঃ সামন্ত লাল সেন

সমর্থযোগী

শেখ হাসিনা জাতীয় বার্থ ও প্লাস্টিক সার্জারী ইনসিটিউট, ঢাকা।

এবং বার্থ ও প্লাস্টিক সার্জারী প্রকল্পসমূহ, সমগ্র বাংলাদেশ।

নং-৪৫.০০.০০০০.১৫৫.১১.০১৬.১৭- (৫৭৮/১০)

তারিখ: ১৩.১০.২০১৯ ইং

অনুলিপি (জ্যোতির ভিত্তিতে নহে) সদয় কার্যালয়ে ও জ্ঞাতার্থে

- ১। পরিবার সচিব, পরিবার সচিব, প্রেসিডেন্সি, সেপ্যুনবাগিচা, ঢাকা।
- ২। মহাপরিচালক, ইমিগ্রেশন ও পাসপোর্ট অধিদপ্তর, আগারগাঁও, ঢাকা।
- ৩। মহাপরিচালক, স্বাস্থ্য অধিদপ্তর, মহাপালী, ঢাকা।
- ৪। যুগ্ম-সচিব, নিরাপত্তা-২ অধিদপ্তর, সুরক্ষাসেবা বিভাগ, স্বরাষ্ট্র মন্ত্রণালয়, বাংলাদেশ সচিবালয়, ঢাকা।
- ৫। জেলা প্রশাসক, ঢাকা।
- ৬। রেজিস্ট্রার, বিএমডিসি, ২০৩, শহীদ সৈয়দ নজরুল ইসলাম সরণী, বিজয় নগর, ঢাকা।
- ৭। সচিব মহোদয়ের একাত সচিব, স্বাস্থ্য সেবা বিভাগ, স্বাস্থ্য ও পরিবার কল্যাণ মন্ত্রণালয়।
- ৮। সিডিল সার্জন, ঢাকা।
- ৯। ইমিগ্রেশন অফিসার, হযরত শাহজালাল আন্তর্জাতিক বিমান বন্দর, ঢাকা।
- ১০। অতিরিক্ত সচিব (হাসপাতাল) এর ব্যক্তিগত কর্মকর্তা, স্বাস্থ্য সেবা বিভাগ, স্বাস্থ্য ও পরিবার কল্যাণ মন্ত্রণালয়।

(মো: আবু রায়হান মির্জা)

উপসচিব

APPENDIX 28: MINISTRY OF HEALTH PERMISSION (ENGLISH)

Republic of Bangladesh Government
Ministry of Health and Family Welfare
Department of Health Services
Government Health Management-1
Bangladesh Secretariat, Dhaka

No. 45.00.0000.155.11.016.17.

Subject: Approval of arrival and stay in Bangladesh for Foreigner (British) Physiotherapist

Reference: Letter number 99 of Sheikh Hasina Burn And Plastic Surgery Establishment Project, Dhaka, dated 25.03.2019

As per above mentioned subject and reference, the approval of arrival and stay for academic purpose of the foreigner (British) Physiotherapist has been provided as written in the bellow table and the condition written beneath to follow:

Sl no.	Name of the medical professional	Nationality	Objective of coming to Bangladesh	Where the medical professional will be working	Duration for stay
1	RuthAnn Marie Fanstone	British	Academic Tour	Sheikh Hasina Burn And Plastic Surgery Institute	From 04-05-2019 for 2 weeks

Conditions:

- (a) To obtain BMDC registration in 7 days and inform the Health Department
- (b) There will be no financial liabilities of Bangladesh government while entering and during stay in Bangladesh
- (c) The Ministry of Home Affairs, Ministry of Foreign Affairs, Ministry of Health and Family Welfare should be informed of your entry and stay in Bangladesh
- (d) Only allowed to provide services/train in designated institution. Not allowed to perform private practice or work in any other institution during the stay as mentioned above
- (e) After completion of the tour, in seven days the applying institute will submit a full independent report to the health department and
- (f) After the period, the departure report of the mentioned physiotherapist should be submitted to the department

Signature

Abu Raihan Miah

Deputy Secretary

Phone number

Coordinator:

Burn and Plastic Surgery Project

Sheikh Hasina Burn and Plastic Surgery Institute,

Dhaka

No. 45.00.0000.155.11.016.17.

Dated 04/04/2019

APPENDIX 29: DMCH ETHICAL APPROVAL FINAL STUDY



ঢাকা মেডিকেল কলেজ
DHAKA MEDICAL COLLEGE
Dhaka, Bangladesh



Memo No. MEU-DMC/ECC/2019/309

Date: 19/10/2019

Ethical Clearance Certificate

The Ethical Committee of Dhaka Medical College Approved the Following Protocol.

Title of the Research Work: "Identification of the Risk Factors in Burn Contracture formation".

Principal Investigator:

Dr. RuthAnn Fanstone
PhD Global Burn Trauma
Centre for Global Burn Injuries Policy and Research
U.K.

Supervisor:

Dr. Mohammad Rabiul Karim Khan
Associate Professor
Sheikh Hasina National Institute of Burn and
Plastic Surgery.

Place of Study:

Department of Burn and Plastic Surgery
Dhaka Medical College Hospital, Dhaka.

Duration:

October 14, 2019 to November 20, 2019.

Prof. Dr. S.M. Shamsuzzaman
Head, Department of Microbiology &
Chairman,
Ethical Review Committee
Dhaka Medical College, Dhaka.

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