Understanding the discordance between Patient Reported Outcome Measures and Clinician Reported Outcome Measures in patients managing with burns scars

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Declaration

I declare that the research presented in this thesis represents original work that I carried out during my candidature at Oxford University, Green Templeton College. To the best of my knowledge, it contains no material previously published or written by another person, except where due reference is made in the text.

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COVID Impact Statement

This work was completed during the Covid-19 pandemic. The data collection period from May 2021-November 2021 relied on patient footfall into the Stoke Mandeville Scar Clinic for face-to face assessment. Due to contact restrictions consultations became virtual and footfall reduced. This led to a reduction in the number of patients anticipated to be seen during the data collection period.

Patients would have had the opportunity to complete PROMs while they waited in the clinic, on an electronic system provided – whether PC or Tablet. This would have increased the number of patients presenting with PROMs to the clinic and thus increasing the data set available for analysis and potential statistical significance of results.

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Abstract

Burns result in an estimated 180 000 deaths annually worldwide. Non-fatal burns remain among the common causes of trauma and lifelong disability. The scars are a reminder of the trauma a patient wears for life. The scar may have a significant impact on the patient's ability to return to work, form new relationships or engage in their pre-morbid activities. A multidisciplinary team approach to the management of the scarred patient is of paramount importance. Care must be individualised and patient-centric. In order to achieve this, Patient Reported Outcome Measures (PROMs) are vital however few burns specific outcome measures exist. The application of Clinician Reported Outcome Measures (ClinROs) remains the mainstay for treatment end points in many specialities, yet these do not always reflect the patient-centric needs. Applying the Manchester Scar Scale ClinRO with the CARe Burns scale PROM to the multidisciplinary scar clinic at Stoke Mandeville Hospital, this study identifies there is a variable level of correlation between the measures according to patient age with some statistical significance.

Burn injuries are multifaceted and the variable correlation in the outcome measures may be due to the heterogenous nature of injuries. Through review of the patient injury journey, this study demonstrates there may be a relationship with TBSA and the patient or clinician perceived outcome.

There may indeed be "hidden domains" not captured by the outcome measures. Though patient interviews and qualitative data review, novel work is conducted to investigate whether injury liability may have an effect on the PROM in burns care and preliminary investigations are made into injury liability.

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Chapter 1 – The structure of burns care in England and Wales and the role Clinical Outcome Assessments

Burns result in an estimated 180 000 deaths annually worldwide. Non-fatal burns remain among the common causes of trauma and lifelong disability (1, 2).

Every clinical intervention pertained to the injured patient is with the end goal of restoration in form and function – the goal being 'scar-free healing'. Burn care strategies aim to accelerate re-epithelialisation and modulate the inflammatory response of the patient to their injury. Treatment of a burn aims to restore the function of the skin – attempting to return to the premorbid state of unimpeded range of motion, hair growth and sweat generation, barrier, and homogenous pigmentation. Standard practice involves the removal of the burned skin and coverage with autograft if the donor site allows, or allograft if the burn is too large.

Burns management structure in the England and Wales

In the UK approximately 175,000 people with burn injuries visit the Emergency Department, with 16,000 of these admitted for treatment. 1,000 patients annually are admitted with burn injuries severe enough to require fluid resuscitation and half of these are children under 16 (3). Following reports by the National Burns Committee in 2001, national policies were defined for the standardised care of patients sustaining burns – understanding that such injuries require specialised care to achieve good outcomes, reduce long-term scarring and prevent other on-going problems (2). The populations of England and Wales were subsequently divided to be served by 4 burns networks: Northern, Midlands, South West UK and London South East (Figure 1). There is a hierarchical nature of burns care specialism across England and Wales:

- Burn Facility equates to the level of in-patient care afforded by a standard plastic surgery ward allowing for the care of patients with non-complex burn injuries.
- Burn Unit will care for those with a moderate level of injury complexity via a separately staffed specialised burn ward.
- Burn Centre is the highest level of burn inpatient care. The ward is separately staffed with specialist healthcare professionals for critical care, is geographically discrete from other wards and has immediate access to operating theatres.

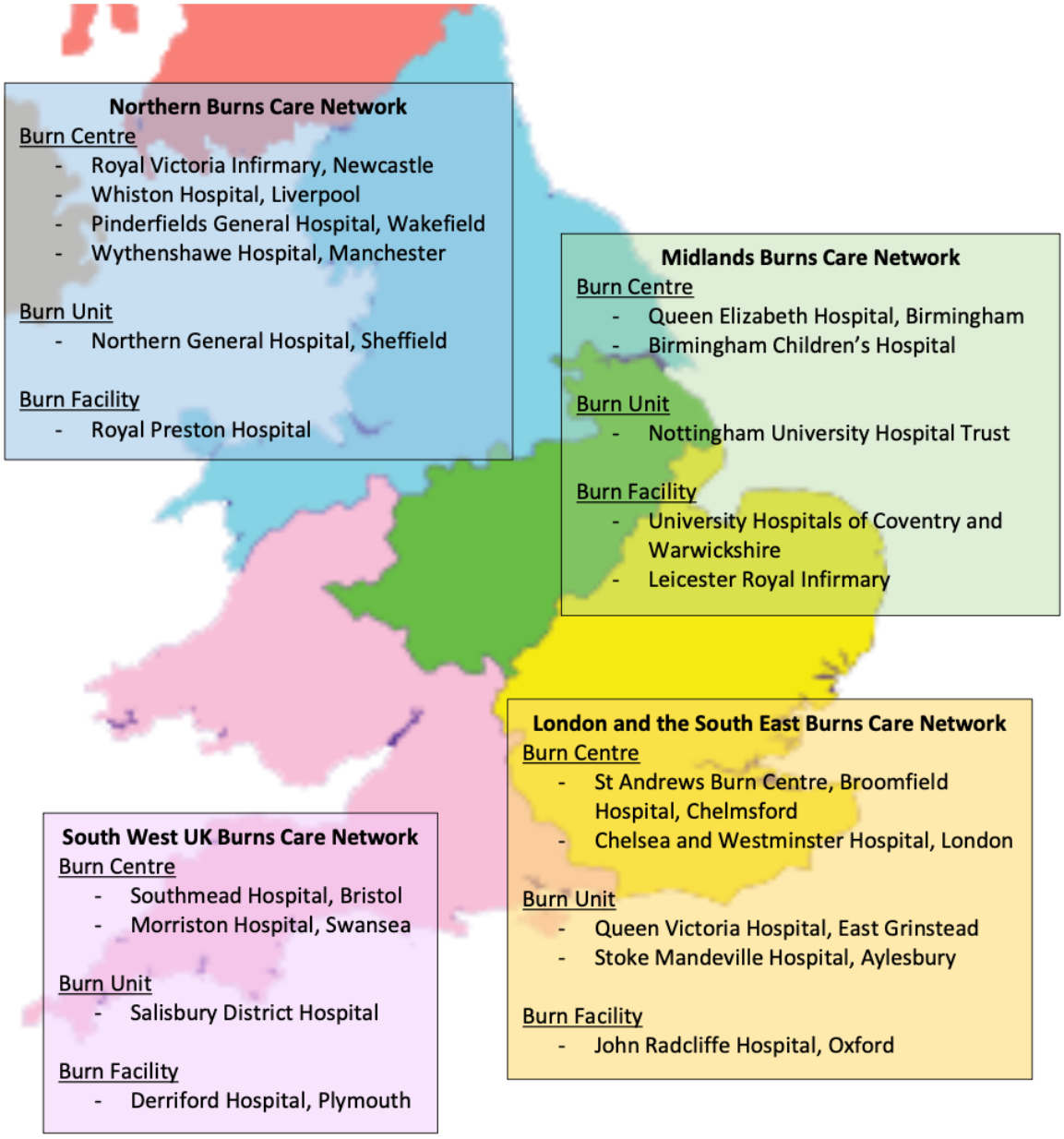


Figure 1 – Map of the UK identifying the regional boundaries of the UK Burns Network

Management of a burn injury

Burn injuries are complex and their management is determined by a host of factors. Major factors in determining patient management include TBSA involved (measured as a percentage), burn depth and the age of the patient being treated, however other factors such as burn mechanism, whether there is an inhalational component to the injury, co-morbidities, patient frailty and concordant trauma, influence geographical location of treatment and clinical approach. When managed by the burns team, the Baux score is calculated as a prognostic tool based on the patient age and TBSA burn which predicts mortality, and has been used since its introduction in 1961 (4). In 2010 this was revised to include inhalational injury as an additional dichotomous variable (5).

Beyond the acute stabilisation of the patient, the journey can then be considered in three stages: burn debridement, wound coverage and scar management.

Burn debridement

Dead tissue covering a burn wound has a negative impact on healing – it provides a medium for microorganisms. As early as 1947 it was noted that early burn excision and autografting both reduced infection and increased graft take (6). This rationale was widely adopted with the introduction of tangential excision in 1970 (7). The current treatment approach remains as simple wound cleaning to remove devitalised tissue and blisters on more superficial burns and tangential excision for deeper burns. It has been established that early debridement is essential for deep burns, which should be debrided and covered, ideally within 24 hours (8). Dermal preservation has been identified as important in burn healing, with apocrine glands and hair follicles acting as keratinocyte reservoirs in re-epithelialisation. Within human models it has been demonstrated there is a threshold depth in wounds penetrating the deep dermal layer of skin that will result in scarring (9). In the mixed depth burn therefore,

tangential excision risks over-debriding the dermis, removing these reservoirs and delaying re-epithelialisation. Work has been undertaken investigating the role of chemical debridement in specific patient cohorts such as those with mixed depth burns, ventilated patients or those not fit for a general anaesthetic. Schultz et al compared the use of Nexobrid (a bromelian derived enzyme approved in Europe in 2012), to tangential excision debridement and reported superior late scar outcomes on hands and faces. This was deemed to be a result of the enzyme only removing the non-viable tissue thus allowing for more dermal preservation (8). Hydrosurgery has a role in the debridement of superficial mixed depth burns, more commonly in the paediatric cohort. Experiences documented by Cubison and Pape as a case series comment on its superior ability to preserve undamaged dermis and maintain a clean wound bed for the application of biological dressings (10).

Wound coverage

Multiple reviews exist globally documenting the various burns wound coverage, from simple non-adhesive dressings, to biosynthetic coverage and various allograft or autograft combinations. Dressing choice is most commonly determined on a case-by case basis by the burn depth – whether partial or full thickness, and the demographics and co-morbidities of the patient. Following a review of coverage methods that may promote wound healing, van der Whal et al determined that it was the burn depth that was the greatest predictor for scarring (11). Reflecting on dressing options, a randomised controlled trial confirmed the use of silicone dressings reduced pain on dressing change, improved healing rates and reduced eschar formation (12, 13). Regarding antimicrobial coverage to reduce infection (a complicating factor that can increase the risk of scar formation in burns), work has demonstrated that sustained-release silver products have a bactericidal action providing effective management of odour and exudate, thus reducing the risk of wound colonisation with pathogens (14, 15). The need for improved patient comfort, infection control, and increased rate of re-epithelialization has led to the development of biosynthetic membranes.

A standard of care for means of selection of these dressings is yet to be established. The composition of collagen, cellulose or a synthetic co-polymer makes these dressings flexible, durable and particularly favourable in paediatric patients (16-19). For patients undergoing surgical debridement for deeper burns, allograft or autologous split thickness skin graft (SSG) are common-place, again depending on burn size and patient circumstances. Successful coverage with autograft necessitates a sufficient donor site availability and, in light of the scanty dermis in the graft harvest, will heal with some degree of contraction (20) and potentially a "fish-scale" skin texture when meshed to expand coverage (21). Developments in wound coverage continue with the goal of scar-free healing as a central theme.

Scar management

Scar is defined as the macroscopic disturbance of the normal structure and function of skin and is formed post maturation phase of wound healing. An immature scar is often pink, raised and pruritic. They mature over 12-24 months to be paler, softer and flatter. In abnormal scar maturation the proliferating cells can result in hypertrophic or keloid scarring. The former describes a raised lesion that does not extend beyond boundaries of the original injury and can regress over time. A keloid scar conversely will not regress with time and can extend beyond the margins of the original injury. The longer the burn takes to heal, the greater the risk of abnormal scarring. It has been shown should a burn take more than three weeks to heal the risk of hypertrophic scarring ranges from 32-72% (21-23).

Conventional scar therapy consists of moisturisation and massage, pressure garments and topical silicone. However, there is only low-quality evidence in support of these practices (24), although some document improved burn scar pliability with prolonged pressure garment use. Utilising these garments come with their own set of limitations, (mainly adherence to the treatment) requiring garment wear for up to 23 hours a day; a significant undertaking for the rehabilitating patient (25, 26). In certain cases, corticosteroid has been

effective in softening and flattening scars, as is also the case when combined with CO_2, pulsed-dye or Nd: YAG lasers (27, 28).

When assessing the outcome of burn management there are a range of parameters that are important to the patient, the clinician, or both. These outcomes may have varying importance according to whether the assessment is completed by the clinician or by the patient. The outward appearance of the scar may be a factor affecting the patient's psychological response to the injury or their social re-integration and relationship formation. The functional impact of scar contractures can limit the range of movement and may alter the ability to return to pre-morbid activities of daily living and additional hobbies. Workplace absenteeism for the treatment of scars or workplace modifications required to allow the patient to return to work may also have the potential to affect the perception of their scar outcome. Scar complications such as itch, pain and tightness may impact the patient perceived scar outcome in the short term, however these symptoms tend to improve over time. It has been identified that appearance-related issues with their scars often persists. It is down to the enduring nature of the outward aesthetic of the scar that can play a central role in burn scar outcome measures. It is a central and lasting problem that is significant to both patients and clinicians. A multidisciplinary (MDT) team approach to the management of the scarred patient is of paramount importance. Care must be individualised and patient-centric. In order to achieve this, Clinical Outcome Assessment (COA) tools, namely Patient Reported Outcome Measures (PROMs) and Clinician Reported Outcome Measures (ClinROs) are vital (29).

Clinical Outcome Assessment Tools

Historically, medical practitioners have taken a paternalistic view on the practice of medicine, treating patients according to the clinician perceived best interest. This paternalistic practice was arrived at through clinician experience and antiquated societal norms. However, there has been a trend towards increased patient autonomy within healthcare: patient-centred care whereby patient values should guide clinical decision making (30-32). Patient centred-care is deemed to be any process of decision making in healthcare that is focused on patients. Those patients will have played an active role in their own healthcare determination by engaging meaningfully. Clinical teams delivering care must ensure it is "respectful of, and responsive to individual needs, and values", interacting with patients as "partners" in the treatment activity (32). With clinical teams having a comprehensive understanding of patient and caregiver priorities in their healthcare, there is increased patient satisfaction and consequently treatment adherence. It has been shown that active patient engagement with care results in a better patient perception of outcome, even if they then cease to engage with the regime (33). It also highlights areas in which there is clinician and patient priority mismatch, opening channels of exploration to align these primacies in future interactions (Figure 2).

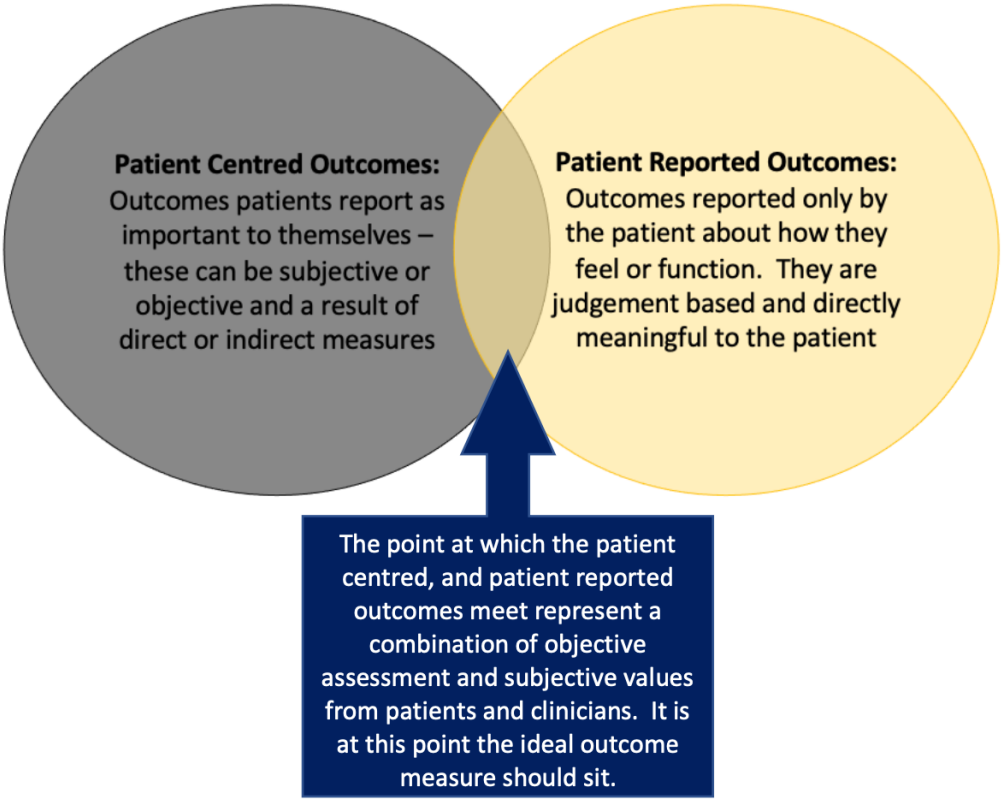


Figure 2 – Defining the differences between Patient Centred Outcomes and Patient Reported Outcomes

In order to understand the outcomes of treatments and the impacts these may have on patients, clinicians and additional parties, Clinical Outcome Assessment (COAs) tools have been devised. COAs are a generalised term for tools used to measure the overall symptoms and mental state of a patient. It gives the patient and healthcare professional both a subjective and objective view of their disease condition and provide means to enhance patient centred care. COAs can be subdivided into four categories:

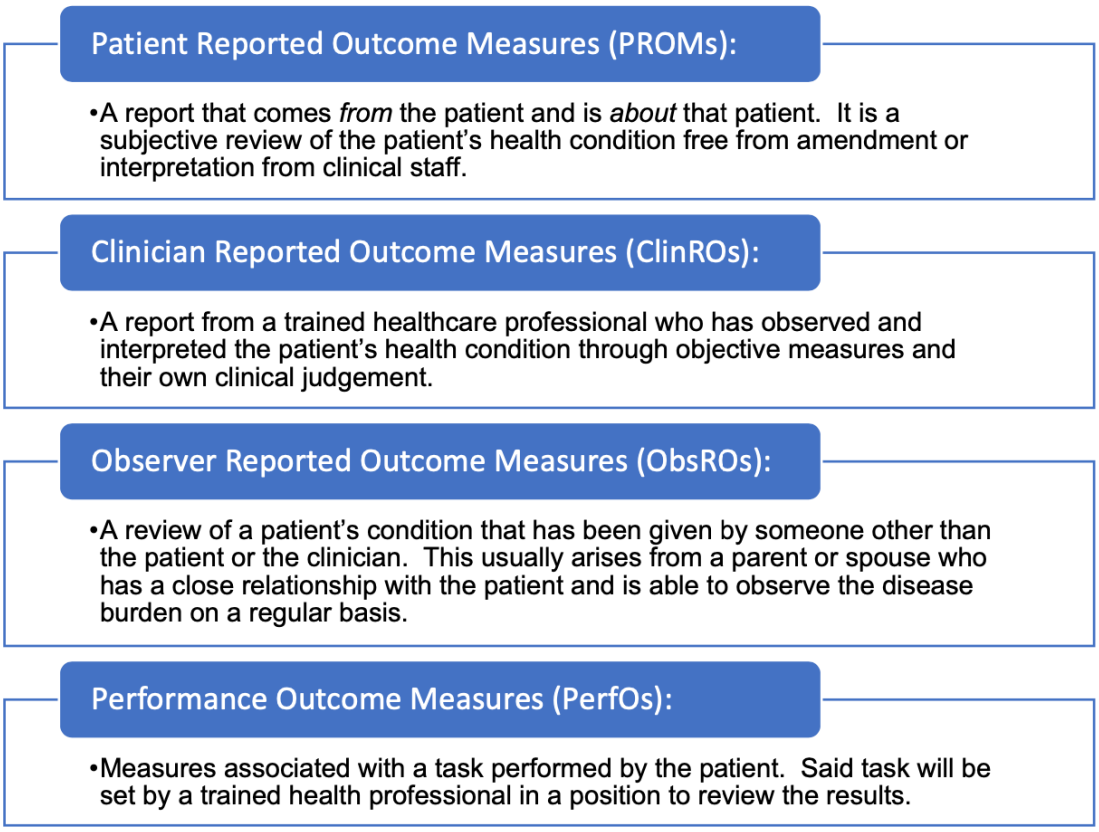


Figure 3 – Outline of definitions of outcome measures used within clinical practice.

Patient Reported Outcome Measures

Patient Reported Outcome Measures (PROMs) are defined as a standardised questionnaire completed by patients to generate a self-report of their own health status. Their use ensures that the patient views are heard and incorporated into the assessment of their care. Cumulatively these PROMs from patient cohorts can influence overall care delivery within a service, power research studies and determine best-practice in treatment delivery (34-37).

For a PROM to be used within clinical practice, it will have undergone rigorous testing to assess validity and reliability within the patient population of focus. This testing enables a PROM to be deemed fit for purpose as an effective tool to measure the aspects of patient health they aim to capture. PROMs have been increasingly used to

support patient centred care, moving away from more clinician centred outcome measures and that paternalistic healthcare model (37).

In generating a PROM, the goal of therapy is being assessed – in essence helping patients live both longer and better. Patients play a central role in PROMs development. Through the conceptual stage, specific queries must be answered as summarised in Table 1 (38).

Domain	Expanded
Which concepts are important to the patient and should therefore be measured?	Biopsychosocial status of health
How should these items be worded?	Simplicity of language used
Are the questions understandable	Will the question be interpreted in the same way by all patients
Do different patients interpret the questions in the same way?	Does the concept in question transcend regardless of educational or cultural background
Is the recall period appropriate in the questions?	In the last week… In the last month…
Does the response scale make sense?	Employment of a Likert scale
What is the optimum data collection mode?	Face to face consultations vs. telephone interviews vs. paper/electronic form questionnaires

Table 1 – proposed stages of PROM development as per Claes and Poels (38).

PROMs are used in both clinical practice and research to establish specific patient needs and assess therapeutic progress. Many PROMs have been developed and validated in multiple clinical and research settings to provide specific information for various disease states and conditions. These condition specific PROMs tend to have a greater validity and sensitivity to change, however there is a role for more generic PROMs such as the Health Related Quality of Life (HRQoL) questionnaire where a disease specific measure is not available. Indeed the UK NHS Next Stage Review highlighted the key role PROMs play in evaluating various healthcare services and informing the commissioning and regulatory body decisions (39).

Although the National Burns Care Review demonstrated that PROMs were not regularly in use in the setting of managing burns patients, their relevance was not overlooked. In the document, the need for rigorous patient centred outcome measurement has been reinforced (3). There are multiple burns specific PROMs available to clinicians to support the care and decision making with their patients. This will be explored in Chapter 2.

Clinician Reported Outcome Measures

As defined, a Clinician Reported Outcome Measure (ClinRO) is a report that comes from a trained healthcare professional post observation of a patient's health condition. The ClinRO evolves from clinical judgement, interpretation of observable signs or behaviours and manifestations of the disease condition. Importantly, a ClinRO is unable to measure the symptoms known only to the patient - in the context of burns and scars this would be commenting on such presentations as pain or itch (40, 41).

Unlike PROMs, ClinROs are based on objectivity to an extent, however clinician bias risks augmenting ClinROs; there is potentially a level of subjectivity to observations when making a global assessment of the patient. There is an antiquated dogma that the patient themselves may indeed be biased against their own health condition and the clinician is the only one truly able to assess them (40). With the increasing use of PROMs in the healthcare setting, it is clear the patient is central in interpreting their own health status.

According to the ISPOR Task Force, there are three definite forms of ClinRO (42):

1. Readings

This is a dichotomous report such as the presence or absence of a fracture on plain film radiograph.

2. Ratings

   A categorical scoring system taking a longitudinal view of a health presentation – such as the evolution of a skin lesion between top-to-toe surveys.

3. Globals

   Also referred to as the Clinical Global Impression, this is an overall judgement on the patient health status or specific aspect of a patient condition. This is the most subjective of the ClinROs as how the assessment is made is not clearly defined and tends to rely on clinician experience. The heterogeneity of this form of assessment can make them challenging to interpret, resulting in an absolute lack in inter-rater reliability.

With objective necessity being the foundation of ClinROs there is a risk some of these measures are irrelevant to the patient priorities. A numerical laboratory result identifying disrupted renal function secondary to hypertension gives the clinician an indicator for urgent pharmaceutical intervention. Conversely the patient may remain asymptomatic and feel inconvenienced by yet another medication to incorporate into their routine. Without considering the patient concerns, the clinician risks patient alienation and treatment non-adherence (43). This crudely highlights the necessity for obtaining shared outcome priorities between doctor and patient.

From a study published in 2021, all-cause mortality was not identified as the most important outcome to patients despite this remaining to be the only outcome measure requiring no patient or clinician judgement (44). With this in mind it is the individual

PROM therefore, that is the most meaningful to the patient – ergo incorporating patient satisfaction into any outcome measure is of paramount importance to current and future practice.

Getting ClinROs right has significant impact on the ongoing care of the patient. In 1965, in the Journal of Pulmonary Medicine, Fletcher noted that clinicians had a tendency to ignore their own errors and avoid discussions with colleagues regarding patient disease states for fear this would result in a converse ClinRO (45). The understanding of the importance of ClinROs has thankfully evolved, with multiple validated measures allowing for inter and intra-rater reliability. However, clinician opinion remains central, rightly or wrongly. Despite the shortcomings that ClinROs appear to have, it is important to note that they were developed with good intentions. They were developed in isolation of a given disease parameter which would then be modifiable by treatment. What the ClinRO fails to address however, is whether this modifiable parameter was one deemed to be important to the patient. Clinician identified *important* outcomes are often assumed to therefore be important to the patient and it is here the weakness of a ClinRO may lie. This does not make the ClinRO superfluous in medical practice, however with the development of PROMs they become a useful adjunct rather than the sole determinant of interventional success (46-48).

Aim

This study aims to explore PROMs and ClinROs in the context of long-term outcomes after burn injury, and to identify how these two tool types may highlight divergent information.

Study research questions

1. What are the most appropriate outcome tools for use in a regional burns unit to document Patient Reported Outcome Measures and Clinician Reported Outcome Measures?
2. Can patient reported outcome measures and clinician reported outcome measures be used simultaneously when assessing the long-term outcomes after burn injury?
3. Is there concordance between the chosen patient reported outcome measure and clinician reported outcome measure in the assessment of burn scar outcomes?
4. Are there any trends in the patient's burn injury that correlate with the chosen Patient Reported Outcome Measure and the Clinician Reported Outcome Measure in this study?
5. Does patient liability in adult burns have any impact on the Patient Reported Outcome Measure?

Structure of this thesis

This Chapter 1 has discussed the structure of burns care in England and Wales and introduced the role of PROMs and ClinROs.

Chapter 2 presents the current literature on PROMs specific for assessing patients with burns and gives justification for the use of the CARe Burns Scale within this study. In conjunction, scar assessment ClinRO tools are reviewed, with the Manchester Scar Scale (MSS) being selected for application to our patient cohort.

Chapter 3 presents the application of PROMs and ClinROs in the Stoke Mandeville Hospital Scar Clinic when reviewing burns. It looks to identify whether there is discordance between the PROM and ClinRO in this clinical setting.

Chapter 4 is hypothesis forming and reviews the patient clinical journey to identify any similarities in the patient pathway that may have led to discordance between PROMs and ClinROs within the patient cohort.

Chapter 5 proposes there are “hidden domains” important to positive patient growth after a burn that is not captured by the current PROMs or ClinROs through the use of patient interviews and an exploration into the patient liability in sustaining their injury.

Chapter 2 – Patient Reported Outcome Measures and Clinician Reported Outcome Measures: selecting appropriate measures for managing patients with burns scars in the Scar Clinic setting of a National Burns Unit – Stoke Mandeville

Introduction

The WHO estimates that 11 million burn injuries of all types occur annually worldwide, 180,000 of which are fatal (2). According to the National Burn Care Review in 2001, it was estimated that 250,000 people per year suffer from burn injuries in the UK, with 175,000 of these patients attending Emergency Departments (3). Healing after a burn injury deep enough to impact the dermis is a complex process often resulting in scarring. A biopsychosocial approach to the assessment and management of the resulting scar is required to understand the impact the injury has had on the patient's well-being and thus the patient perception of their wound outcome. Impact can range from functional deficit through pain, itch, chronic wounds and contractures to psychological or social factors impeding the return to work or the formation and maintenance of relationships.

A systematic review by Lawrence et al (2012) investigated the epidemiology and impact of scarring after burn injury and concluded there was a lack of burns specific psychometric outcome measures (23). Others have noted that summarising the state of burn outcome knowledge was nigh-on-impossible due to the heterogeneity of study designs and outcomes measures previously employed (49).

Clinical decision making for personalised management of burns scars is dependent on factors such as patient experience and clinician expertise, however the use of standardised outcome measures has become increasingly prevalent to garner more in-depth knowledge of the

patient condition. This is of particular significance in burns care as although there is a high global incidence of injury (1)**,** such outcome reporting heterogenicity results in ongoing uncertainty regarding optimal patient management.

When considering Clinician Reported Outcome Measures (ClinROs) in burns, these are scar measurement tools documenting ***appearance***. There is a well-established knowledge base when it comes to describing the risk factors associated with scar development, with time to healing, (regardless of intervention – surgical versus conservative management), seemingly the most determinant (50-52). An exhaustive exploration reviewing the clinical records of 703 patients with burn injuries was completed by Gangemi et al with a view to establishing the most significant risk factors in developing burns scars complications. In the study it was found that risk factors included gender (female > male), young age, multiple surgical procedures, burn depth, use of meshed skin graft and the burn affecting the neck and upper limb (50).

Collecting PROM data is not a standard practice across UK burns facilities, units or centres with departments potentially having their own method of data collection and patient satisfaction groups. At the time of writing, there is no nationally recognised outcome measure or centrally managed database for mandatory incorporation of these PROMs to allow for cross-centre comparative studies. The International Burn Injury Database (iBID) is in the process of incorporating the Patient and Observer Scar Assessment Scale (POSAS) 2.0 but presently this is not an obligatory component of the record.

It is estimated the annual operative burden globally is over 200 million patients, be that elective or trauma – 1 in 25 of these will suffer from a scar (53). Scar assessment is a recognised adjunct in the ongoing management of the patient to direct the need for further clinician intervention. Where PROMs assess the patient perception of the burn as a

multifaceted entity incorporating domains relating to physical activity and mental well-being, the subjective measure is the visual scar, which can be captured by ClinROs. This can be a beneficial addition to clinical assessment when reviewing the maturation of a scar or the outcomes of an intervention. Again, ClinRO application is not standard practice across burns facilities, units or centres across the UK.

Up to 100,000 children and adolescents suffer burns annually in the UK alone. Advances in medical and surgical treatment has meant an increasing number of these patients are living with the ramifications of their injuries (54). These patients are already coping with complex developmental milestones in life and the addition of struggles associated with the trauma and ongoing management of burns and scars can add further pressure (55-57). A 2013 study noted that children and adolescents who have experienced burns in their formative years are at increased risk of anxiety and affective disorders in adulthood (57). Children and adolescents are treated in different wards, by different specialists when they suffer a burn compared to adults with similar injuries, therefore a different approach to their outcome measures would logically ensue. They may require alternative support from their adult counterparts to reduce the risk of experiencing long term difficulties associated with their injuries sustained in these formative years. Specific PROMs developed for children and young adults are therefore key in identifying and addressing these needs appropriately. It was determined by the MDT the PROMs applied to the Stoke Mandeville scar clinic should have domains that focus on the heterogeneity of the cohort attending: adults, young people, children and their caregivers.

Of note, from the systematic review completed by Griffiths et al (29) only four of the burn-specific PROMs identified had been validated in the English language: three for adults and one for young adults: the Burn-Specific Health Scale – Abbreviated (BSHS-A) (58**),** the Burn-Specific Health Scale – Brief (59)**,** the Burn-Specific Anxiety Scale (BSPAS) (60) and

the Young Adults Burn Outcome Questionnaire (61). Only one scale had been validated in paediatric burn care: Children Burn Outcome Questionnaire for children age 5-18 (CBOQ) (62). Since this time, the CARe Burns scales and Brisbane Burn Scar Outcome Scales have been developed and validated in the English language.

In this study, we aimed to implement PROMs and ClinROs to all patients attending the burns scar clinic at Stoke Mandeville Hospital. Further details on the clinic setting are discussed in Chapter 3. Early phase research was required to select the appropriate PROM and ClinRO tool that would be applicable to the real-world clinic setting. This Chapter describes the existing literature for burns specific PROMs and ClinROs and justifies the chosen example of each to be used in the data collection in the Scar Clinic.

Research Question

What are the most appropriate outcome tools for use in a regional burns unit to document Patient Reported Outcome Measures and Clinician Reported Outcome Measures?

Methods

The decision was made to not complete a systematic review in light of multiple recent publications of PROMs and clinician outcome measures in burns (29, 63-66). The work was conducted by a sole researcher. There is risk this could have given rise to bias, affecting the validity of a systematic review, therefore a robust literature review has been undertaken. The early phase research of this project was not intended to answer the clinical question of which outcome tool is superior to another, instead it

assisted in providing context to inform the decision as to which PROM and ClinRO tool would be the most appropriate to use in our clinic setting.

A literature review was performed in PubMed, EMBASE and Scopus for all available published articles up to 31st December 2021 to identify English language articles relating to English language generated PROMs and ClinROs. For PROMs the search terms included "(scar assessment tools)", "(scar) and (patient reported outcome measures) or (PROMs)", "(burn) and (patient reported outcome measures) or (PROMs)". For ClinROs search terms included "(scar assessment tools)", "(scar) and (clinician reported outcome measure) or (ClinROs) or (CROMs)", "(burn) and (clinician reported outcome measures) or (ClinROs) or (CROMs)". All original studies, and systematic reviews were included. Only texts originally written in English were included. All duplicate articles were discounted. Inclusion and exclusion criteria are summarised in Table 2.

Inclusion Criteria	Exclusion Criteria
• Articles written in the English language • Articles using PROM or ClinRO – any age group • Articles utilising PROMs or ClinROs in generated in the English language – any age group	• Articles written in languages other than English • Articles utilising PROMs or ClinROs in languages other than English • Articles reporting outcome measures in patients who had not sustained a burn injury • Articles commenting on scar outcomes not sustained through burn injury • Articles reporting the use of objective measurement tools in outcome measures

Table 2 – Inclusion and exclusion criteria for articles identified in literature review pertaining to PROMs and ClinROs used in the assessment of burn scars.

The search identified articles that described tools used to assess traumatic, surgical and burn scars. Within this, articles that did not specify their use in burn scars were discounted. Identified objective tools used to measure burn scars in clinical trials, most commonly surface area, scar thickness, pliability, relief (skin surface irregularities), and colour (67), were

reviewed. Despite these tools being deemed objective and giving quantifiable results in burn scar assessment, none of the tools were available for the study we planned to conduct within the Scar Clinic setting and therefore lacked the feasibility required, as summarised in Table 3 (67-71). The articles assessing objective scar assessment tools were therefore discounted from the literature review.

Tool	Objective measurement	Limitation for this study
Scar tracing **Photography** **Stereophotogrammetry**	Surface area of scar – assess for the expansion or contraction of scars	Scar tracing, although simple is time consuming Photography relies on the in-clinic availability of Medical illustration Stereophotogrammetry requires specialist equipment
Tissue Ultrasound Palpation System TUPS) **Biopsy**	Scar thickness	TUPS requires specialist equipment Biopsy is an invasive clinical procedure not feasible for in-clinic completion on a large scale
Cutometer **Tonometry**	Pliability/ skin elasticity	Both tools are specialist equipment not available in our clinical setting
Silflo silicon polymer	Relief	Time consuming to complete so not feasible for real-time clinic use
Narrow- band reflectance spectrophotometry **Tristimulus reflectance colorimetry** **Laser Doppler**	Colour (pigmentation, vascularity)	The devices used to objectively measure vascularity and pigmentation changes are expensive and not available in our clinic setting

Table 3 - identified objective tools used to measure burn scars in clinical trials with the limitations negating their use in this study.

On completion of the literature review, to select the appropriate PROMs and ClinROs for this study, all outcome measures identified were explored in detail and presented to the multidisciplinary (MDT) Scar Clinic team in the unit. The data presented to the

team included in-depth discussion of all burn specific outcome measures and tabulated summaries of their reliability and content validity. Clinic feasibility was reviewed at the time of data presentation. The domains measured by both PROMs and ClinROs were also summarised and presented for a consensus to be reached as to the most appropriate outcome measure tools for the use in this Scar Clinic. At this time, the priorities of the MDT were explored with regards to what information was needed to be captured in clinic. A further MDT meeting resulted in the rejection of tools deemed inappropriate for this clinic setting and a consensus on a ClinRO and PROM was agreed.

Results

A total of 91 articles were identified as meeting the search criteria. Among these, 22 tools were included in burn scar assessment: 18 PROMs, 3 ClinROs and 1 combined measure.

Clinician Reported Outcome Measures in burns care

Burn- induced Cosmetic Disfigurement: rating colour-side photographs

First developed by Smith et al in Shriners Burns Unit, Boston in 1988 this is the earliest described ClinRO specifically related to burn scarring available on review of the literature. Using colour-slide photographs from 30 patients, both clinical and non-clinical observers were required to rate the burn scars according to irregularity, thickness, colour and overall cosmetic disfigurement. 95 observers were enrolled, and each photograph underwent 4-to-8-person assessment (72).

Vancouver Scar Scale (VSS)

Globally one of the most commonly used ClinROs assessing scar outcomes post trauma, and specifically burns (73, 74), this scale contains four domains – vascularity, scar height, pliability and thickness. It generates a score from 0-14, the higher the value, the worst the outcome is considered to be (75, 76). Despite its popularity, it is regularly modified, making it a difficult scale to validate with many variations having no validation (74, 77). Regardless of the modifications, at its conception it was shown by Baryza and Baryza to have acceptable internal consistency and a moderate inter-rater reliability.

Manchester Scar Scale (MSS)

The MSS is a multi-item categorical scale that employs an additional visual analogue scale (VAS). It utilises scar descriptors to assist the clinical evaluation. The domains include scar contour (flush, indented, hypertrophic or keloid); scar colour compared to the surrounding skin; skin to scar distortion; scar texture; sheen (whether matt or shiny), and a global assessment score. Assessing 69 patients over a ten-month period in the mid 1990s, a scale was developed by Beausang et al in Withington Hospital, Manchester as a response to the team's perceived lack of a robust objective scar assessment tool. Each patient was reviewed by the same single clinician and scored from 1-4 in the four domains (bar whether matt or shin being scored out of 2). A global assessment from 1-10 was also given to the scar – the lower the score here, the worse the overall appearance. The global assessment score was added to the score from the visual analogue scale to mark the scar from 5-28 in total. Validation of the scale was completed using 36 photographic panels and ten clinicians. The generation team also carried out histological assessment of the scars to understand if these findings correlated with their observer scores (78). The authors demonstrated inter- and

intra-rater reliability however, there is no evidence of its application in further clinical studies. This is perhaps due to the VSS being more internationally recognised, with many having a prior understanding of, or experience in using that tool.

Patient Reported Outcome Measures in burns care

Burn Outcome Questionnaire (BOQ)

- *Children Burn Outcome Questionnaire for children age 5-18 (CBOQ)*
- *Caregiver proxy questionnaire for children age 0-5 (BOQ 0-5)*
- *Young Adult Burn Outcome Questionnaire for ages 18-30 (YABOQ)*
- *Adult Burn Outcome Questionnaire (ABOQ)*

Daltroy et al identified the need for a standardised questionnaire to assess the impact of burn injuries in the child and adolescent patient group. The developed scale not only showed reliability but also demonstrated potential for sensitivity to change on repeated tests as the patient developed (79). Within the systematic review by Griffiths et al investigating PROMs used in the child and adolescent population with burns, they found that within 23 studies, 32 different PROMs were used (63). Within this review, only the C-BOQ was validated and had psychometric evidence relevant to the specific population of children and adolescents with burns. The C-BOQ contains 52 items with 12 subscales assessing multiple child specific domains including parental concerns and their return to studies. It was devised through literature review and expert opinion and showed evidence of internal consistency, test-retest reliability and validity within the scale. It was also deemed to show acceptability within the adolescent patient population (age 11-18).

All of the BOQ questionnaires came out of Shriners Hospitals for Children/American Burn Association. The team determined all of the BOQ tools were developed from established frameworks including those from the Medical Outcomes Study of 1989 (80). These were then piloted with interviews with adolescent burn patients and parents to develop item content. For the CBOQ, over 1,200 paediatric burns patients and their guardians completed the questionnaire, indicating acceptability and feasibility in the clinical setting.

From CBOQ, the Shriners Hospitals for Children/American Burn Association team developed the BOQ 0-5, a proxy questionnaire for guardians of the child with a burn. A 55-item form was applied to 184 age-appropriate patients' parents/ guardians which demonstrated good internal consistency, scale reliability and validity of the form.

The Shriners team later developed the Young Adults Burn Outcome Questionnaire (YABOQ), published in 2013. It was devised through literature review and the expert opinion of the Shriners team. Unlike the CBOQ development, Ryan et al utilised patient opinion in draft versions of the tool. The questionnaire consists of 47 items and identifies 15 domains and is the result of expert opinion, factor analysis and testing of scale assumptions to inform item reduction. It encompasses physical function (gross and fine motor); symptoms such as pain and itch; perceived appearance; social functionality that may be limited by their burn injury; family perceptions: family unit function, concerns and religion; symptom relief satisfaction and reintegration into work. The tool included 153 burned and 112 non-burned patients who completed the questionnaire at initial contact, 10 days, 6 months and 12 months – over 620 questionnaires - which provided the psychometric evidence for YABOQ. Since its construct in English, it has been translated and validated into multiple languages for global application (81) and has demonstrated internal consistency and reliability. Interestingly, with its use of augmented existing generic Health Related Quality of Life (HRQoL) domains its outcomes are also relative to comparison with non-burned cohorts. Taking free discussion

patient feedback from the team at Shriners Hospital for Children they noted “it opened lines of communication with the doctor,” and “helped organize (my) thoughts on burn recovery”. As with all PROMs it was limited by patient literacy (61).

The ABOQ was the most recent of the tools to be devised (2018). The 14-item questionnaire was devised through the previously validated YABOQ and administered to 120 adult patients with burns, across three units, who were aged over 18-years old. The tool contained the same domains as YABOQ, without religion, however has only one question per domain with the intention for it to be used during clinic time rather than as pre/post clinic augment or stand-alone research tool (82).

Brisbane Burn Scar Impact Profile (BBSIP)

- *Brisbane Burn Scar Impact Profile for children aged 8-18*
- *Brisbane Burn Scar Impact Profile for Caregivers for children aged 8-18*
- *Brisbane Burn Scar Impact Profile for Caregivers for children aged under 8*
- *Brisbane Burn Scar Impact Profile for Adults*

The BBSIP tools were devised by the Australian team of Tyack and at the time were the first known multi-dimensional health-related PROMs that incorporated patient and parental interviews for its construction (n=30) (83). In generating their PROMs a systematic review by Spronk et al (84) identified there was a need for an easily accessible, burn specific tool for symptom self-report by children. Additionally, it identified the role of the caregiver as a proxy for children aged 8-18 years with their own reporting scale. The scales include 10 domains assessing: the overall impact of the scar; symptom (sensory) frequency/intensity/impact; mobility and daily living including climbing stairs and sitting down; social interactions/friendships; appearance; emotional reaction and physical symptoms.

Patients reported that scar tightness was of particular concern and therefore the BBSIP reflects this with three sub-questions to explore the extent of this. In the caregiver scale, sensory domains of intensity and impact are replaced with family concern and parent worry. They met developmental guidelines as per Cano et al (85) and conducted interviews with burn patients and relatives as part of their tool design, however the BBSIP scale authors comment that the sample size and retention of participants in development and testing was a limitation to the design. Due to geographical constraints within the Brisbane centre, some data was collected through telehealth consultations supported by the burns centre, rather than face-to face interactions. This then relied on local centres scheduling follow-up appointments for test-retest, which was not completed, resulting in the required participant number for scale validation testing not being met. Despite the sample size constraint, the BBSIP authors were able to demonstrate construct validity in those completing repeated measures. The authors also report that further studies are underway with a larger sample size along with a longer follow-up period to establish validity, with factor analysis to guide potential item deletion.

Since development of the scales they have undergone validation studies and further psychometric analysis. In adults 118 participants were tested at baseline (when >85%TBSA had re-epithelialised) with 57 remaining for the 1-week and 1- month re-test. In caregivers, 86 participants completed the tool at baseline with 42 completing at both interventional stages. For children 65 were tested at baseline (with median age 12 years) and 26 completed the questionnaire at both interventional stages. The authors identified in their psychometric studies that the scales demonstrated reproducibility, longitudinal validity, responsiveness and interpretability however noted some redundancy of items that warranted further investigation. Psychometric studies were completed with Australian adults (n=23), children (n=19), caregivers of those with burns scars (n=28) and international scar management experts (n=14).

CARe Burns Scale

- *CARe Burns Adult scale – age over 18 years*
- *CARe Burns Young Person scale – age 8-17 years*
- *CARe Burns Child scale – parental completion for patients aged 8 and under*
- *CARe Burns Parent scale – parent with child of any age with a burn*

Systematic reviews were conducted from January 2001 to March 2013 (with search re-runs for adult PROMs in May 2015 for contemporaneous capture) investigating PROMs used in adult and children/young person burn research. Searches identified 77 different PROMs being used, however it determined there were only 4 that were burn-specific, with no scales relevant to all ages coming from the same centre in the same time period (29, 63). Only 20 adult and 3 child/adolescent PROMs within the systematic review search demonstrated some level of psychometric development. Four of these were specific to adult burns and one specific to paediatric burns. The review noted the extent to which these burns specific PROMs had been validated in line with the Medical Outcomes Trust guidelines for PROM development varied (85).

Resulting from the systematic review of PROMs specific in burns care, the UK based team devised the CARe Burns Scale: a suite of self-reported burn-specific PROMs that have been rigorously developed following a recommended, gold standard protocol (85, 86) with input from burns patients who had received treatment in the NHS Burns Service, their family members and health professionals across the UK. Patients were involved from the start of item generation and in scale drafts, making the domains relevant to the investigated patient cohort. In validation stages, item reduction was directed by Rasch analysis. This tested each item within the domains and removed those poorly functioning through bias or

ambiguity. It strengthened the PROM for use in identifying clinical change – beneficial in real-world clinical settings and research studies.

The adult scale is for those aged over 18 years and has 14 domains with 53 items: wound/scar discomfort; wound/scar treatment; wound/scar dissatisfaction; physical well-being; social situations; avoidance behaviours; self-worth; negative mood; work life; family support; friend support; intimacy; trauma symptoms; positive growth. The Young Person scale is for those aged 8-17 and has 9 domains of 51 items: wound/scar discomfort; wound/scar treatments; wound/scar dissatisfaction; physical well-being; social situations; self-worth; negative mood; romantic relationships (aged 12 and over); positive growth. The Child scales is completed by the caregiver in those aged 8 and under. It consists of 6 domains and 32 items: wound/scar discomfort; wound/scar treatment; parental wound/scar dissatisfaction; physical well-being; social and emotional difficulties; social and emotional well-being. Finally the Parent scale is for any parent with a child (of any age) with a burn injury experience and consists of 8 domains and 40 items: physical well-being; confidence in helping with wound/scar care treatment; social situations; partner relationship; self-worth; negative mood; parent dissatisfaction for the child's wounds/scars; positive growth.

Satisfaction with Appearance (SWAP) scale

The SWAP scale is the first validated PROM scale developed for patients with burn scars, regardless of their age. First described by Lawrence et al (1998) it was determined the previously established outcome measures for understanding disfigurement or scarring post trauma were irrelevant for burns patients. The scale was developed from a literature search combined with expert opinion and is a measure of scar outcome satisfaction (87). Subsequent systematic reviews have noted in the scale generation that there was no mention by the authors of a conceptual framework, nor were there documented patient interviews conducted

(29). There was however patient input on earlier drafts of the scale (resulting in amendments prior to clinical and research use), in addition to patient opinions and clinician expertise informing the item reduction phase. Taking components from the antiquated Body Image Dysmorphia (BID) scale, originally developed through the study of eating disorders (88), a 14-point summation was prepared. This incorporated subjective appraisal from the patient regarding their scar and social-behavioural components. A high Cronbach alpha score established homogeneity within the questionnaire items. Trialled on a cohort of 165 patients it demonstrated a high level of internal consistency and test-retest reliability (when repeated by 84 participants at two-months). Assessment by patients and clinical experts allowed for content validity to ensure relevance of the items and representation of the clinical condition being investigated (87). Thombs' longitudinal study of body image in burns survivors (2008) identifies the benefits of repeating the SWAP scale at intervals as a measure of patient development and adaption following injury (89). Despite this work, there remains no current published literature reporting the scale's responsiveness in the adult burn population. Following translation into Portuguese for use in Brazilian burns units it was noted by clinical and research teams that the SWAP scale should be part of the burns assessment armamentarium and not the sole outcome measure for the biopsychosocial adaptation of the specific patient cohort, as it lacked domains in well-being and mental health (90).

Burn Specific Health Scale: –Abbreviated (BSHS-A), -Revised (BSHS-R) and -Brief (BSHS-B)

- *Burn Specific Health Scale – Abbreviated*
- *Burn Specific Health Scale - Revised*
- *Burn Specific Health Scale - Brief*

Patients subject to polytrauma require a multidimensional approach to assess their recovery. In 1979, Blades et al recognised there was not only the need for specific injury assessments

but that those suffering from burns were a unique sub-set that may face challenges other trauma patients did not (91). Their team developed the BSHS from a set of generic health measures via literature review and expert opinion. There were no patient interviews in the conception phase however patients did review drafts of the scale before it was clinically applied– originally a 114-item questionnaire (92).

User fatigue and domain overlap were among the limitations of the early BSHS and through item reduction based on expert opinion, the BSHS-A was developed: an 80-question form on a 5-point Likert scale covering the themes of physical, mental, social and general health (93). Early studies by Munster et al demonstrated the BSHS-A to have high levels of internal consistency and reliability in all domains, and acceptable validity (93, 94). Despite this, there was a lack of construct validity within the BSHS-A and intercorrelation between categories and sub-categories, resulting in poor factor analysis (93, 95, 96).

To address the shortcomings of the BSHS-A, the scale was revised in 1994 by Blalock et al to the BSHS – R (97). Their team enrolled a cohort of 254 former patients and identified treatment regimens and heat sensitivity as sub domains to replace general health and sexual activity – the latter being incorporated into an interpersonal relationships domain. The BSHS-R demonstrated a high level of internal consistency (Cronbach alpha 0.82-0.94).

The BSHS-B was generated through further factor analysis (99, 100). A Swedish study by Willebrand and Kildal in 2008 conducted second order factor analysis to remove the "work" subscale leaving only: affect and relations, skin involvement and function, however later factor analysis finalised the domains and subscales to be: physical function (simple abilities and hand function); work; skin involvement (heat sensitivity, treatment regimes, body image); affect and relations (affect, interpersonal relations and sexuality) (101).

Burn Specific Pain Anxiety Scale (BSPAS)

The Burn Specific Pain Anxiety Scale was devised by Taal et al in 1997 (102) and abbreviated in 1999 (103). It is a nine-item scale solely focused on the assessment of the pain and anticipatory anxiety suffered by burnt adults. The abbreviated form was generated through burn patient interviews with no documented evidence of any other means of scale development, such as literature review or expert opinion. It was devised using a small sample size of 35 adults and there was limited evidence regarding its validity. In order to improve scale validation, the team expanded to a multicentre study incorporating 173 burn patients sub-categorised into three groups according to their TBSA. Perhaps unsurprisingly anxiety was elevated in patients with larger burns than those with smaller when the scale was implemented on patients prior to burn care procedures (103). Despite the multicentre trial improving reliability of the scale, its narrow subject matter in the context of the full assessment of a burn patient has meant its clinical use is somewhat limited. A sole study based on 27 English speaking adult burn patients has been identified that provided limited psychometric evidence of the abbreviated scale.

SCAR-Q scale

The SCAR-Q scale was developed via a combination of qualitative datasets, cognitive interview and expert opinion (105). Although this scale is utilised for all types of scarring (surgical, traumatic and burn related), the cohort involved in development was not comparable and was not a burn-specific scale at conception. It has been identified by Blades et al that burns patient form a very specific subset of trauma survivors who will have their own specific healthcare priorities (91). Despite this, the study has significant strength in its development utilising a large sample of participants and making no apologies for

specifically focusing on patient perceived scar appearance as their outcome measure with three domains: scar appearance, scar symptoms and the psychological impact of the scar.

Unfortunately, in the development stage of this scale, no burn scars were actually included in the content validity. To make the scale applicable to burn scars, cognitive interviews with scarred patents (injured through alternative means) were then overlaid with expert opinion. On field testing of the SCAR-Q scale however, Ziolkowski et al enrolled
184 burn patients out of the overall 731 strong test cohort, concluding the scale to be internationally applicable, rigorously developed and relevant to scar evaluation in both clinical care and research settings (106).

POSAS

The POSAS is a combined outcome measure with a patient and an observer domain. It is a 7-item questionnaire scored on a 10-point Likert scale and can be used on all types of scars. The patient scale measures scar characteristics: irregularity, colour, stiffness and thickness, patient symptoms of itch and pain, the scar compared to normal surrounding skin and requests a global overall score. The observer scale records scar thickness, pliability, vascularisation, pigmentation, relief, TBSA and like the patient scale has a global assessment score. A score of 7-70 in each scale is generated, with a higher score indicating a worse perceived outcome.

The first iteration of POSAS was devised in Dutch and introduced in 2004 (107). It was generated post literature review and wide scale expert opinion. Shortly after, POSAS 2.0 followed with minor adjustments and was made available in thirteen languages. At time of writing, POSAS 3.0 is due to be launched at the 2022 European Burns Association meeting. The authors of the POSAS report the scale can be used in both research and clinical settings

to measure the effectiveness of scar treatments and used as a tool to assess scar maturation over time. There was no documentation in the original article by the authors relating to any other methods used in devising the PROMs that met Medical Outcomes Trust guidelines for PROM development (85).

The POSAS demonstrated evidence of validation in English speaking burns patients. The PROMs itself is a generic PROMs focused on scar, not specifically devised for burns patients. Van der Wahl et al sought to complete psychometric analysis on the tool and found through Rasch analysis the scale to be reliable in providing a unidimensional measure for scar quality, except in the TBSA component of the Observer scale (108). Work by De Jong et al advised scar assessment is multidimensional and the scale in its current form does not give an overall sense of patient perception of their scar and has no variables accounting for patient age (109). Of note, the validation of the POSAS arose through the evaluation of a scar area measuring 3x3cm. Although the Observer Scale makes comment on the overall TBSA, this is not a domain available to the patient, therefore the quality of the scar in one discrete area may be variable to that of another. Studies have sought to evaluate the patient perception of the total scar through POSAS which resulted in the formation of three further dimensions to review the concepts of self-esteem, socialisation and return to pre-morbid functional roles. The authors have commented that further high-order multi-dimensional assessments are required to develop these themes (109).

Presentation to the MDT

The results of the literature review for ClinROs and PROMs were tabulated and presented to the Stoke Mandeville Scar Clinic MDT for a consensus on outcome measure relevance and feasibility in this specific outpatient setting. The reliability, clinical relevance and thus content validity of identified tools were extracted from the published literature and

summarised (Table 4). Reliability tools within studies have been quantitatively expressed via Intraclass Correlation Coefficient (ICC) or Cohen's Kappa coefficient (κ) to provide inter-rater reliability (obtaining the same results between different raters) or intra-rater reliability (gaining the same results from the same rater on subsequent reviews). Clinical relevance relates to whether the domains of the tool are important to the patients, clinicians or researchers. Comments are made on whether the tools have been applied clinically or had all parties involved in the tool generation. Additionally, with members of the MDT, feasibility was applied in relation to the tool being used in the Stoke Mandeville Scar Clinic. The MDT considered if it could be effectively implemented contemporaneously in a clinic setting, in essence, could the tool be applied to all patients seen without impacting the time a patient had to discuss their burn outcome and plan future management.

In addition to the literature review completed, work in 2013 from Tyack et al and Choo et al in 2021 provided context and assistance to the MDT when considering the appropriate ClinRO (73, 71).

	Reliability	Content Validity	Clinic feasibility
PROM			
Adult Burn Outcome Questionnaire (ABOQ) Children Burn Outcomes Questionnaire: CBOQ; BOQ11-18 Parental proxy: BOQ0-5 Young Adults Burns Outcomes Questionnaire (YABOQ)	No evidence identified Good in BOQ5-18 and BOQ 11-18 (ICC = 0.75 – 0.92 Good in BOQ0-5; parent proxy (ICC = 0.82 – 0.93) Good (ICC = 0.72-0.92) test-retest reliability 0.29-0.74	<u>CBOQ and YABOQ:</u> Literature review, expert opinion, patient reviewed drafts of scale, development of conceptual framework, item reduction, psychometric analyses	All devised in USA Questionnaire can be applied prior to or during clinic time Real time iPad application piloted in YABOQ
Brisbane Burn Scar Impact Profile for Adults (BBSIP) Brisbane Burn Scar Impact Profile for Children (8-18)	Moderate to good (ICC = 0.65-0.83) Good- acute period 8-18 (ICC=0.71–0.83) Mobility + friendship outlier ICC = 0.52 and 0.45	Systematic review, devised through qualitative datasets, cognitive interviews with patients + expert opinion POSAS used as tool to validate against new scale	Questionnaire can be applied prior to or during clinic time Devised in Australia

Caregivers (0-8 and 8-18)	Moderate to good (ICC = 0.65-0.83)		
CARe – children + young people CARe – parent proxy CARe Adult	Moderate-good (ICC = 0.53-0.75) Moderate to good (ICC = 0.62-0.80)	Systematic review, expert opinion, patient interviews, patient reviewed drafts of scale, development of conceptual framework, item reduction, psychometric analyses	Questionnaire can be applied prior to or during clinic time Devised in UK
Satisfaction with Appearance (SWAP) scale	Moderate (ICC 0.31-0.52)	Literature review and expert opinion	Questionnaire can be applied prior to or during clinic time
Burn Specific Health Scale: – Abbreviated (BSHS-A), -Revised (BSHS-R) and -Brief (BSHS-B)	No evidence identified	Literature review + expert opinion on revisions of scale	User fatigue precludes full BSHS
Burn Specific Pain Anxiety Scale (BSPAS)	Good (ICC = 0.71-0.82)	Pilot with patient + nurses expanded to multicentre application	Questionnaire can be applied prior to or during clinic time; domains limited to pain and anxiety
SCAR-Q scale	Good (ICC = 0.88-0.94)	Devised through qualitative datasets, cognitive interviews + expert opinion	Questionnaire can be applied prior to or during clinic time
ClinRO			
Burn- induced Cosmetic Disfigurement: rating colour-side photographs	Good (ICC= 0.94)	Expert opinion	Time consuming for real-time clinic application. Limited by resources – access to medical photography
Vancouver Scar Scale (VSS)	Moderate (κ = 0.40-0.56) (ICC = 0.53)	Widely applied in burns literature	Apply during clinic time Additional time required for scar height measurement
Manchester Scar Scale (MSS)	Evidence not identified	Clinically relevant descriptors and + correlation with histological findings in development Independent clinician review of photographic panels in scale generation	Devised for application by sole clinician/researcher Apply during clinic time
Combined			
POSAS 2.0	Observer reported domain: Moderate to good (ICC = 0.59-0.73) Patient reported domain: Moderate to good (ICC = 0.65-0.81)	Literature review and expert opinion Applicable for sole researcher Patient and Clinician domains require completion – no evidence of validation in single party completion (patient/clinician)	Applicable for sole researcher Apply during clinic time

Table 4 – Summary of the literature search of outcome measures used in burns scar assessment: reliability, content validity and clinic feasibility

The domains of interest measured in the ClinROs (Table 5) and the PROMs (Table 6) were summarised and presented to the MDT.

	Colour	Surface area	Vascularity	Colour mismatch	Pigmentation	Pliability	Thickness	Relief/irregularity	Additional domain	Global assessment	Applicable in clinic
Burn Induced Cosmetic Disfigurement	✓	*x*	*x*	*x*	*x*	*x*	✓	*x*	*x*	*x*	*x Four observers required*
VSS	✓	*x*	✓	*x*	✓	✓	✓	*x*	*Co-morbidities: itch/pain*	*x*	*x Height measurement difficult to reproduce*
MSS	✓	*x*	*x*	✓	*x*	✓	✓	✓	*Sheen/ matt*	✓	✓

Table 5 – Summary of the scar measurement domains of the identified ClinROs used in burns care.

	BSPAS	SCAR-Q	BSHS	BSHS-A	BSHS-R	BSHS-B	CBOQ	YABOQ	ABOQ	BOQ 0-5	BBSIP adult	BBSIP child 8-18	BBSIP caregiver <8	BBSIP caregiver 8-18	SWAP	CARe Adult	CARe Young Person	CARe caregiver <8	CARe caregiver – any age
Scar insecurity	✓																		
Pain – intrusive thoughts	✓																		
Pain – affecting activity	✓							✓	✓										
Pain - fear	✓																		
Future pain anxieties	✓																		
Fear – loss of control	✓																		
Scar appearance		✓									✓	✓	✓	✓					
Scar symptoms		✓	✓		✓	✓	✓	✓	✓	✓	✓	✓				✓	✓		
Psychological impact on well being		✓	✓	✓	✓	✓					✓	✓				✓	✓	✓	✓
Interaction with family				✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓			
Interaction with friends/				✓	✓	✓	✓	✓	✓				✓	✓	✓	✓			
Interaction with strangers															✓				
Intimacy								✓	✓		✓	✓			✓	✓	✓		
Attraction									✓						✓				
Sexuality			✓	✓		✓													
Fatigue - general									✓										
Fatigue – burn scar											✓								
Overall scar satisfaction															✓				
Overall impact of scar											✓	✓							
Mobility/ physical function				✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓					
Fine motor function			✓	✓		✓		✓	✓										
Completion of activities of daily living			✓								✓	✓	✓	✓					
Emotional reaction								✓	✓		✓	✓	✓	✓			✓	✓	✓
Work			✓		✓	✓		✓			✓					✓			

School																			
Observed symptom frequency										✓			✓	✓				✓	
Parental worry/ family concern							✓	✓	✓	✓			✓	✓					
Perceived appearance								✓	✓										
Satisfaction with symptom relief								✓	✓										
Satisfaction with role/ role activities				✓				✓	✓										
Religion								✓											
Body image			✓	✓	✓	✓													
Treatment regimes			✓		✓	✓										✓	✓	✓	✓
General health				✓															
Wound/scar dissatisfaction																✓		✓	✓
Avoidance behaviours																✓			
Social situations																✓			
Self-worth																✓	✓		✓
Negative mood																✓	✓		
Parental relationship with partner																			✓
Trauma symptoms																✓			
Positive growth																✓	✓		
Parental wound/scar dissatisfaction																		✓	✓

Table 6 – Summary of the scar measurement domains of the identified PROMS used in burns care.

When considering the most appropriate PROM for the MDT Scar Clinic setting, the scales were also reviewed and presented to the team as per the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) initiative (110-112). The guidelines from COSMIN stipulate reliability, validity and responsiveness be represented to assess the quality of the PROM proposed:

- Reliability – the measurement is free from measurement error, or if present, to what degree?
- Validity – the degree to which the PROM measures the outcome it asserts to capture
- Responsiveness – can the PROM detect change over time?

	BSPAS	SCAR-Q	BSHS	BSHS-A	BSHS-R	BSHS-B	CBOQ	YABOQ	ABOQ	BOQ 0-5	BBSIP adult	BBSIP child 8-18	BBSIP caregiver <8	BBSIP caregiver 8-18	SWAP	CARe Adult	CARe Young Person	CARe caregiver <8	CARe caregiver – any age
Reliability																			
Internal consistency		✓						✓			✓	✓	✓	✓	✓	✓	✓	✓	✓
Scale reliability		✓						✓							✓	✓	✓	✓	✓
Measurement error		✓						✓			✓	✓	✓	✓		✓	✓	✓	✓
Validity																			
Content validity	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Construct validity	✓							✓			✓	✓	✓			✓	✓	✓	✓
Criterion validity	✓	✓									✓	✓	✓	✓	✓	✓	✓	✓	✓
Responsiveness				✓	✓			✓											

Table 7 – Assessment of reliability, validity and responsiveness of the proposed PROMs tools, as per the COSMIN initiative.

With all evidence collected, the MDT met to discuss their priorities for the PROM and ClinRO to be used in the Scar Clinic. The PROM was required to be validated in English, cover all ages that attend the clinic, have a robust conceptual framework involving patients in outcome design and have the breadth of domains to review the biopsychosocial impact of the burn.

The study intended to be conducted in the Stoke Mandeville Scar Clinic- a UK setting. The majority of patients and practitioners being native English speakers, the English language validation of the proposed PROM was deemed important by the MDT in the scale selection process. On review of the validation process it was identified all of the burn specific PROMs had been validated in the English language for adults and young people with burns: BSHS-A, BSHS-B, YABOQ, BSPAS, CARe burn adult, CARe burn young person, and BBSIP adult. Although not specific to burns, the SWAP and SCAR-Q are also validated in the English language. Five PROMs had been validated in the English language for children and caregivers with burns: CBOQ, CARe Burn caregiver <8, CARe Burn caregiver- any age, BBSIP caregiver <8, BBSIP caregiver 8-18.

Regarding the scale application to all age groups, only BOQ, CARe and BBSIP scales had specific questionnaires for adults, children, young people and caregivers. All other scales were generic burns tools that may not represent the heterogeneity of the cohort attending the Scar Clinic in which the scale was to be applied.

As the PROM was specifically being applied to burns patients, the team felt strongly that patients should have had a role in the development of the measure. With this in mind, only

three scales utilised patient interviews at the conception stage: BBSIP, CARe and BSPAS. The remaining PROMs specific to burns care that were identified in this literature search combined reviews of published resources and expert opinion. Of note however, the YABOQ and BSHS did undergo draft reviews by patients before clinical application. The SCAR-Q scale did use patient interview in its design, however these were not burns patients. All scales were considered to have breadth of domains addressing the biopsychosocial impact of a burn, however the BSPAS does not address the social factors of work, school or family that the other scales measure.

The findings addressing the MDT requirements were summarised and presented to the team (Table 8). Only the CARe Burn Scales and BBSIP scales satisfied all parameters. With all the information presented and discussed, the tool selected by the MDT was the CARe burn scale. It was devised in the UK with patients that had burns treated within the NHS service. It has been reported by the authors to be applicable in both research and clinical settings. At present, the scale has not undergone any revisions or augments and will be used as devised.

	Specific scale for each age group encountered in Scar Clinic?	Conceptual framework involved patient interviews in PROM design?	Breadth of domains to examine biopsychosocial impact of burns?	Scale validated in English?
CARe (Adult; Young Person 8-17; Caregiver [0-8, any age child])	✓	✓	✓	✓
BBSIP (Adults; Children 8-18; Caregivers [0-8, 8-18])	✓	✓	✓	✓
BOQ (ABOQ; YABOQ; BOQ 11-18; CBOQ; BOQ 0-5)	✓	X	✓	✓
SCAR-Q	X	✓	✓	✓
BSHS (-A; -R; -B)	X	X	✓	✓

SWAP	X	X	✓	✓
BSPAS	X	X	(✓)	✓

Table 8 – Summary of requirements for Scar Clinic PROMs following the presentation of the literature review and MDT consensus.

In selecting an appropriate ClinRO for the Scar Clinic, the team determined the scale should be simple and time efficient to implement, have a breadth of domains for scar assessment and be able to be completed by a sole reviewer. Table 9 presents a summary of the ClinROs in relation to the MDT requirements.

	Simple to complete	Limited additional clinic time required for completion	Adequate breadth of scar assessment domains	Use as sole researcher
Burn Induced Cosmetic Disfigurement	✓	✓	X	X
VSS	✓	X	✓	✓
MSS	✓	✓	✓	✓

Table 9 – Summary of requirements for Scar Clinic ClinROs following the presentation of the literature review and MDT consensus.

The Burn Induced Cosmetic Disfigurement scale assess only colour and scar thickness. The literature stipulates four observers are required for the scale and an overall decision should be based on expert opinion. Although the study demonstrated that there was inter-rater reliability between the raters, regardless of clinical experience, it fell short when considering feasibility (72). Within the context of our outpatient scar clinic, this number of assessors cannot always be guaranteed in light of conflicting clinical commitments. With fewer observers, the scale would be used in a way not intended by the authors and may lead to inconsistencies in the data collected, so was quickly discounted.

Concerns were raised by the team in implementing the VSS. Although the observation can be completed by a sole practitioner, there were questions raised around the reproducibility of measuring scar height between observers. The objective measuring of a scar can be time consuming when assessing textural scars – commonly viewed in burns. Time constrains in the scar clinic limited the feasibility of this scale. Practitioners also sought guidance on how many height measurements should be taken from a textural scar, which is not addressed in the literature.

The MSS has a broad range of scar descriptors, including a global assessment with a VAS. The MSS can be completed by a sole researcher. With all the information gathered and presented to the MDT, it was determined the MSS would be the ClinRO of choice.

Discussion

The principle finding of this study was that although there are multiple outcome measures available specifically for the assessment of patients with burns scars, few met the requirements for the implementation within this Scar Clinic setting. Through review of the literature, presentation of findings to the MDT and establishing the team's priorities for the outcome measures, the CARe Burns Scale was selected as the PROM and the MSS as the ClinRO.

Patient Reported Outcome Measures

In discussion with the MDT, specific criterion for the PROM were identified as important in this Scar Clinic setting. The PROM needed to have been developed with burn scars as a central theme. This was to allow for in-clinic comparison with the ClinRO for the next stage of this work: to identify where patient and clinician assessment mismatched. The PROM needed adequate domains to investigate the patient perception of the scar and its impact on activities of daily living, to facilitate the MDT in future treatment planning. It should be of adequate length to gain depth of data but not so long that its completion is disincentivised for taking too much time. In relation to questionnaire length, the PROMs would be sent to patients prior to attending clinic. This would allow time in a home environment to complete the questionnaire, with the intention that patient answers would inform the MDT on priorities to address during clinic time.

A consideration for scale selection for the future work that was to be conducted, was its application to all ages attending the scar clinic. The scale therefore needed to be valid in differing age ranges. This was the case for the scales from Australia (BBSIP), USA (BOQ) and UK (CARe). The scale was to be implemented in a UK clinic setting and therefore the BOQ scales, being written in American- English, risked lacking cultural validity as was not applicable to the linguistic groups under investigation. Regarding the BOQ scales, the YABOQ was identified as the most stringently validated of the adult scales from the Shriner's institute. In a letter to the editor response to the systematic review by Griffiths et al (113), the team identified the validation stages of the construct however, the conceptual frameworks from which the scale was lifted from were not developed with adult burn patients at its core. To develop a tool for the adult burn, the Shriners Hospital team designed the ABOQ, however on domain review it lacked comparable granularity to alternative scales now available, such as BBSIP and CARe, whereby each domain is investigated by a single question. For these reasons, the BOQ scales were deemed not appropriate for this research setting.

In the real-time clinic setting, the brevity of the BOQ scales are beneficial however, the MDT proposed sending the scale to patients prior to the clinic for completion at leisure so as not to impact clinical assessment time. The estimated time taken for the CARe burn questionnaire completion is less than 20 minutes, for all of the age specific scales. Although this time-frame is not stipulated in the research data from the publishing authors, members of the MDT completed the scales and found this time estimate to be accurate.

The CARE Burn Scale is the only PROMs tool developed in the UK in a single centre with NHS patient cohort. This made the scale contextually relevant to the Scar Clinic setting for which it was to be applied. Aside from the BBSIP, it is the only scale readily available for free download online for clinical application. The CARe scales have the interpretation table and instruction guidelines also freely available, which the BBSIP presently do not.

Age specific outcome tools have been deemed important in the assessment of burns care. A systematic review by Spronk et al (84) identified there was a need for an easily accessible, burn specific tool for symptom self-report by children. They found children from aged eight are considered to have the cognitive development required to report more complex thoughts and feelings**,** however the BBSIP team demonstrated children up to the age of ten required assistance in completing the tool – particularly if their literacy skills were below the expected standard for developmental stage (114)**.** The BOQ, BBSIP and CARe burn scales all also have caregiver proxy questionnaires however it is only the CARe scale that reports the parental questionnaire is appropriate for caregivers of children or any age.

It is not uncommon for multiple outcome measures to be used to capture all required information by the clinical team. The CARe scales are encompassing tools which have been reported to not rely on additional PROMs to overlap for assessment of the biopsychosocial impact of the burn and scar. Through rigorous scale development, the identified domains the CARe Burns Scale gives a broad data set of information pertaining to the impact of the burn injury to the patient and caregiver. Additionally, the scale has specific domains related to the scar appearance when completing the wound/scar dissatisfaction subset. This would give information to the MDT regarding patient perception of the scar against the observer ClinRO assessment, allowing for exploration in future work as to whether there may be discordance between the outcome tools.

Not every burn specific PROM can cover every possible biopsychosocial factor that may affect patient outcome. In developing the CARe scale, domains not previously captured in PROMs specific to burns were explored, including negative symptoms such as avoidance behaviours and trauma symptoms, and positive domains such as growth after the burn injury. In contrast, a unique domain included in the adult BBSIP is fatigue related specifically to burns. Although the ABOQ captures data on fatigue, this is relating to a general lack of vitality rather than explicitly from the burn scars. Of interest, work completed by Young et al sought to establish a Core Outcome Set for Burn care research with international consensus (COSB-i). The results published in 2022 succeed the commencement of the work completed in the Scar Clinic. For the MDT the features of the ClinRO and PROM were applied to assess the scar appearance along with additional domains relating to positive and negative attributes of the injury, however COSB-i have identified scar appearance to not be considered a core outcome despite its prevalence in multiple scar outcome measures (115). It is unclear from the publication at which stage the outcome of scar appearance was discounted from the core set however it was noted to be the third most prevalent outcome count in conducted interviews on item generation. Interviewees for the item generation included: burn care clinical staff, adult burn patients and a child/parent combination. The core outcomes identified by COSB-i were: death from the burn (or any cause); ability to do daily tasks; time to wound healing; long tern symptoms (neuropathic pain/itch post wound healing); psychological wellbeing; perceived serious outcomes or complications and time to return to work/school. Although the scar appearance is a key outcome measure the MDT are assessing in the Stoke Mandeville Scar Clinic, further work should consider the new published COSB-i guidelines to homogenise international outcome reporting and allow for effective dissemination of meaningful results globally.

Clinician Reported Outcome Measures

A review of scar scales in 2010 by Fearmonti et al highlighted the operator-dependent errors that are raised with all ClinROs in this field, commenting the tools are inadequate at assessing large burns or functional outcomes (116). Despite this, through informal MDT discussions it was proposed the literature search for burn-specific ClinROs be completed, and the results be presented to the team for discussion. Presently the Stoke Mandeville Scar Clinic does not employ any ClinROs. The need for a ClinRO was established in order to give baseline assessment of the patient's scar to reference on subsequent follow-ups and compare treatment interventions. The application of a single scar assessment tool within the Scar Clinic would therefore provide comparable in-house data for future treatment planning within our patient cohort.

Of the ClinROs presented to the MDT, the VSS was the most widely known, however it has been noted in studies to have limitations through insufficient reliability in the assessment of large or irregular scars (117). Multiple modifications have been made to the VSS including the addition of pain or puritic symptoms or adjustment of the scale according to skin pigmentation (118, 119). These additions however have not undergone rigorous validation. The difficulty of rater reproducibility of scar height measurement in a heterogenous scar still remains a difficulty in the context of this Scar Clinic.

Although no published additional studies relating to the MSS investigate the tool's reliability beyond the original article, the tool has the greatest clinical feasibility within this study's Scar Clinic setting. It would capture detailed observational changes if used for follow-up reviews without fear of mis-measuring the scar height component required in the VSS. It is proposed the work completed could add to the literature body to guide future reliability studies into the tool. This has not been explored in this present work.

Limitations

The literature review conducted contained only those PROMSs and ClinROs which had been written in English. It is therefore possible that alternative appropriate burns outcome measures will have been overlooked if devised or validated in a language other than English. Such examples include the Coping with Burns Questionnaire, which has been written in Swedish by Willebrand et al and is yet to have English language validation (120). There is also the potential that units nationwide in the UK, or indeed internationally, are utilising their own departmental PROMs or ClinROs they have devised in-house and are yet to be published. This literature review was a manual online search and neglected to contact specific units within the UK or abroad to determine if they were utilising outcome measures yet to be published.

At present, no published literature found has noted the responsiveness of the CARe burns scales. The implementation of the PROMs into the Stoke Mandeville Scar Clinic setting is de-novo, therefore the lack of evidenced responsiveness data was deemed of little relevance to this context. The scales are proposed to be used regularly in the Scar Clinic after the study completion and therefore this may generate some evidence for the chosen scale responsiveness. This future work has not been addressed in this current study.

The CARe Burn Scale authors accept that ongoing validation work is needed for the scales in the test-retest context to show the scale's ability to detect change over time (121). As the scale is being used as a single snapshot for this study, the lack of evidence supporting the scale's longevity is of little relevance.

Conclusion

The literature review identified multiple PROMs and ClinROs in use for the assessment of burn scars. Of those identified in the review the VSS and Burn Cosmetic Disfigurement scale were not deemed feasible for real-time application as the ClinRO. The POSAS 2.0, although widely used in multiple settings and currently informing the iBiD database, was deemed inappropriate for use in the Scar Clinic as the patient tool limited information pertaining to mental state and wellbeing. Further to an in-depth assessment of the tools and presentation to the multidisciplinary scar clinic team members, the CARe Burn Scale was agreed as the PROM with the MSS as the ClinRO.

Chapter 3 - Utilising Patient Reported Outcome Measures and Clinician Reported Outcome Measures simultaneously in assessing scar outcome after burn injury

Introduction

PROMs are valuable tools in the assessment and management of burn injuries, allowing the collection of information directly from the patient about their health status, symptoms and quality of life. The application of PROMs can be utilised throughout the patient journey from initial assessment: evaluation of the patient regarding pain, physical function and emotional well-being to plan appropriate interventions; to progress monitoring guiding treatment adjustments. Based on PROM results, healthcare providers can tailor treatments to address specific burn patient needs and customise action plans. The use of PROMs allows for Patient-Centred Care, empowering the patient to be actively involved in treatment, expressing their concerns, preferences and priorities thus enhancing communication between patients and healthcare professionals.

The needs of burns patients are complex and heterogenous with their wounds and scarring causing pain, itching, limited range of movement and concerns around aesthetic appearance and self-image. Patients with burn scarring also report demonstrating avoidance activity due to their scars, fearful of engaging with others, apprehensive of unwanted questions (122, 123). The relationship between patient and healthcare provider in the context of burns can be long-term, and in some cases, lifelong therefore establishing a dialogue between patient expectations and clinical capabilities is important. An adjunct to this is the utilisation of ClinROs which offer insight into burn scar characteristics, quality and progression. Additionally they serve a role in functional implications, evaluating how well scar tissue allows for normal movement of the affected body part and reviewing treatment efficacy.

Using PROMs and ClinROs as a conduit to scar assessment identify similarities or differences in patient and healthcare perspectives, opening dialogue for management options and to align outcome expectations.

Within the Scar Clinic setting of Stoke Mandeville Hospital Burns Unit, the MDT burns care team met to discuss the introduction of PROMs and ClinROs into the consultation. Reflecting National recommendations (3) the consensus within the MDT was therefore reached to apply the PROM scale to be completed prior to the clinic in order to highlight patient priorities before attending, thus tailoring the consultation to address their concerns. Domains of importance highlighted in the PROM can lead the discussion within the MDT clinic and direct future management pathways such as scar treatments, psychology sessions or signposting to community resources that may be beneficial.
There is no direct literature pertaining to the use of PROMs and ClinROs simultaneously in the burns scar MDT setting specifically, however Martin et al realised there was little known about the objective measurements of burn scar quality and how this compared with the patient's perception of their scar (124). In this study, the authors explored whether there was any correlation between a ClinRO performed by a rehabilitation therapist using the Vancouver Scar Scale (VSS) and the patient's own view using a visual assessment scale (VAS) on a Likert with two questions:

1) How would you rate your own scar?
2) How do you perceive others view your scar?

Taking a total of 20 adult patients, the VSS was applied at early scar assessment and subsequently repeated 18-months later. From this relatively small adult cohort, there was no correlation at early assessment between the clinical VSS and the patient's visual analogue scale score. Conversely at late assessment there was correlation between the clinical view and patient view of their own scar, yet discordance remained when it came to patient perception of others' view of their injuries (124). In other areas of medical practice

utilising both PROMs and ClinROs, it has been documented there is discordance between these outcome measures. Haro et al compared PROMs to the Japanese Orthopaedic (JOA) score, a ClinRO applied in the assessment of lumbar stenosis decompression (125). They noted that as surgeries are primarily performed to improve patient quality of life, outcome assessments have a responsibility to incorporate patient satisfaction as well as tangible clinical outcome measures. For their PROMs they included the quality-of-life Short Form (SF-36), the Oswestry Disability Index, and a VAS targeting pain. It was shown in their cohort of 42 patients that both PROMs and ClinRO scores improved post-surgical decompression. When the PROMs were combined allowing for symptom assessment and mental health evaluation, there was a significantly higher patient satisfaction when compared to the clinician perception of surgical success. In this cohort, a crucial role was identified for PROMs in the assessment of patients, the requirement for multiple PROMs to ensure all patient domains are addressed and interestingly, discordance between the post-operative PROM being more favourable than the ClinRO (125).

The NHS Next Stage Review: the National Burns Care Review, has identified that PROMs are not consistently used within the UK Burns Services (3). From the study findings, it was noted there was a lack of PROMs designed to assess burns patients within the UK system. Since the release of the review, the CARe Burn Scale was designed by a UK team specifically targeting burns patients, with relevance to their management within the NHS. The scale was developed using the guidelines from the Scientific Advisory Committee of the Medical Outcomes Trust (2002) and Cano et al and psychometrically analysed (85, 121).

The application of PROMs and ClinROs simultaneously is novel within the MDT burns scar clinic setting. This study demonstrates how the outcome measures were applied to the clinic setting and on analysis of the results, what relationships are noted between the patient

perception and clinician perception of the global outcome, with specific view to the scar outcome. Through previous review of the literature and consensus within the Scar Clinic MDT, the CARe Burn Scale will be used as the PROM and the MSS as the ClinRO. For further details on the outcome measure selection, see Chapter 2.

Aims

The primary aims of this chapter are to answer the research questions:

1. Can PROMs and ClinROs be successfully applied simultaneously in a burns scar clinic setting?
2. What additional information does the application of PROMs and ClinROs add to the management of patients in this setting?
3. Is there corelation between the global outcome of the PROMs and ClinRO?
4. Is there correlation between the scar assessment according to the PROM and ClinRO?

Through extrapolation of PROM and ClinRO results in alternative clinical settings, it is hypothesised that there may be a correlation between the global outcome of the PROM and ClinRO within the burn scar setting. The global PROM evaluates additional aspects of the burn, beyond the scar appearance such as family relationships and positive growth, however these factors may impact the patient perception of their scar, therefore it is hypothesised there may not be a correlation between the scar assessment domain of the PROM and the ClinRO since patient and clinician perceptions of the scar may differ (124).

Stoke Mandeville Scar Clinic

At Stoke Mandeville Hospital within the Buckinghamshire Healthcare Trust (BHT), a weekly MDT Scar Clinic is undertaken for patients that have sustained burn injuries. Patients of all ages attend clinic – either face-to-face or remotely through video-link, as a result of COVID-19 restrictions reducing patient footfall. The path to the scar clinic can be reviewed in the flow diagram (Figure 4). All patients attending clinic have been triaged using the chart previously devised in-house by the burns MDT (Figure 5). Those scoring ≥2 are automatically offered a Scar Clinic appointment. Patients that do not fulfil the criteria for immediate clinic referral however can also request attendance if they feel a follow-up would be of benefit.

The members of the MDT in attendance at the Scar Clinic include a Burns Consultant, a Specialist Burns Nurse (Advanced Care Practitioner), Physiotherapist, Clinical Psychologist, and a Junior Doctor. Clinic appointments last twenty-minutes, during which time patients have the opportunity to discuss their scar with all members of the MDT and address scar symptoms, functional restrictions and the impact on quality of life.

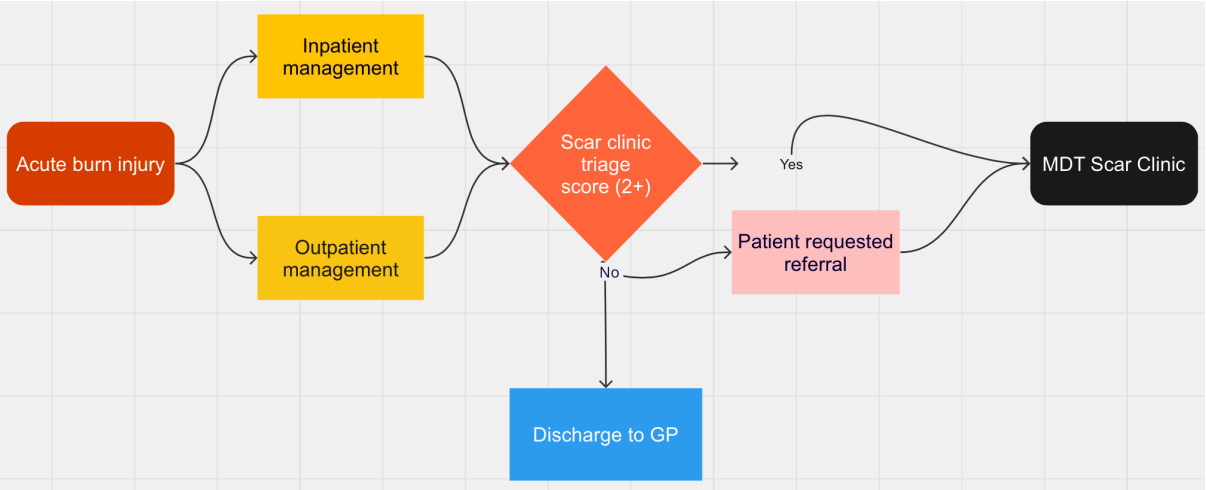


Figure 4 – Flow diagram outlining the patient pathway to the Scar Clinic following the acute burn injury.

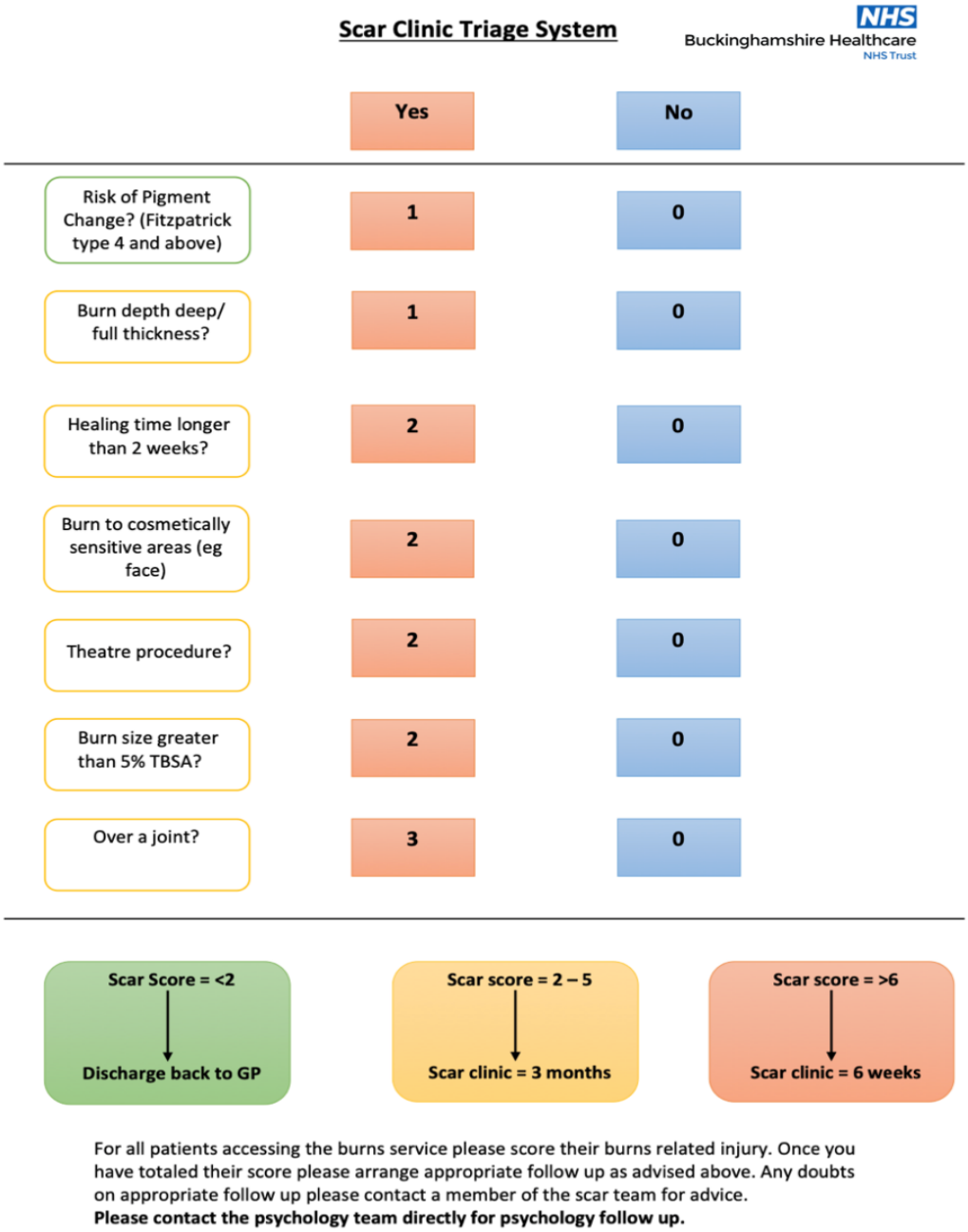


Figure 5 – Triage tool designed in-house at Stoke Mandeville Hospital to determine the need for scar clinic follow-up post management of the acute burn injury.

Methods

All necessary approvals were obtained to conduct the study – the work was deemed to be a Quality Improvement project by the Trust's Research and Innovations Committee, therefore no additional ethical approvals were required.

Application of PROMs and ClinROs in SMH MDT Scar Clinic

The CARe Burns Scale was input verbatim into the Qualtrics XM data capture platform, a GDPR compliant data storage platform currently in use within multiple NHS Trusts UK-wide. The electronic form was then sent via email to all patients listed to attend the MDT Scar Clinic, consecutively, over a six-month period May-November 2021. The form was sent one week prior to their clinic appointment in order to gather contemporaneous information on the patient's mental and physical well-being. The questionnaire form was compatible with all PC, tablet and mobile devices. No patient was excluded from invitation to partake in the data collection however natural exclusions arose – these being patients who were unable to access the electronic means required to complete the survey and those who did not have an understanding of written English (Table 10).

Patients were requested to complete initial demographic information stating date of birth and relationship to burnt individual – whether they were completing the documentation for self or as a parent or guardian. The results of date of birth and patient relationship determined the CARe Burn Scale that was made available to the individual completing the questionnaire, via selective data expression employed by the Qualtrics XM software.

The possible CARe Burns Scales available to patients were:

- Adult
- Young person (age 8-17)
    A. Question bank completed by the young person
    B. Question bank completed by the parent or guardian questions specific to them
- Child
    A. Question bank completed by the parent or guardian with the child's input encouraged, as a proxy to the child's PROMs

B. Question bank completed by the parent or guardian with questions specific to them

The completed PROMs were then reviewed by the MDT Scar Clinic prior to the patient attending for their appointment. Weighting in the form of time spent with, or team member that led the consultation, was be applied to the clinic interaction depending on patient responses according to which domains of the CARe burns scale the patient may be scoring comparatively lower on in relation to other domains. If a patient was having difficulty with symptomatic scars, the clinician and physiotherapist input took the lead. If a patient was struggling with ideas of self-worth or esteem, the consultation was initiated by the Clinical Psychology team. All members of the MDT were available to the patient throughout the consultation however, the focus of the consultation was dictated by the patient's pre-established needs.

Consent for use of their anonymised data was requested at the opening of the Qualtrics XM powered PROMs questionnaire. Only patients who have consented for the use of their data were included in this study.

Inclusion criteria	Exclusion criteria
- In the acute setting, patients referred to Scar MDT through triage score ≥2 (Figure 5) - In the acute setting, patients requesting follow-up through self-referral with triage score <2 - Patients attending scar clinic between May 2001-November 2001, regardless of the elapsed time between initial burn injury and scar clinic follow-up	- Patients with no access to electronic means for PROMs completion i.e. PC, tablet, smartphone - Patients without understanding of written English - Patients who have not consented for their responses to be used in this study

- All patients attending scar clinic – regardless of whether this was their first encounter with the MDT or as a follow-up appointment - Patients who have consented to their responses being used in this study - Patients who completed PROMs prior to clinic and had ClinROs applied at time of review	- Patients who did not complete PROMs, thus have only ClinRO results

Table 10 – Inclusion and exclusion criteria for data collection in the Scar Clinic patient cohort.

Over the same six-month period, consecutive patients seen in the Scar Clinic, face-to- face or over video connection, had their MSS ClinRO completed by the same sole researcher to maintain consistency.

This augmented clinic structure utilising both PROMs and ClinROs is novel within SMH. No literature exists documenting this clinic structure in regular use within the UK. The structural change of this MDT clinic has been presented at the International Forum on Quality and Safety in Healthcare, Europe in June 2021.

Data Collection and Storage

Patients completing the PROMs and consenting for their data use in this study were selected from the Qualtrics XM platform and downloaded to a password protected Microsoft Excel spreadsheet. Qualitative PROMs responses were transposed to quantitative data as per the CARe Burns Scale analytics tool and input into the intuitive template to review the weighting in response to domains for each patient and to calculate both domain specific and global PROM scores.

Data was transcribed back into password protected Microsoft Excel spreadsheets according to their patient cohort: adult, young person, child- parent/guardian. Their MSS ClinRO total score was applied at time of clinic and input to correspond to the PROM score each patient had provided. The MSS five group parameter score (/18) was recorded along with the VAS (/10 on Likert scale – 10 relating to poor result, 1 relating to excellent result). The lower the total value, the better the clinician perceived scar outcome is. The total of these two results constitute the global MSS as per published (78). Patients were identifiable by their unique hospital numbers and all data stored on password protected programmes and an encrypted flash drive within NHS servers.

Data Analysis Methods

All data analyses were performed using IBS SPSS 29. The Pearson correlation co-efficient equation was used to measure the linear correlation between the global CARe Burn Scale PROM against the MSS ClinRO in each patient cohort. As a separate evaluation the Pearson correlation co-efficient was used to measure the correlation between the PROM sub-group of wound/scar dissatisfaction in adults and young people (and the parent wound/scar dissatisfaction relating to their child) with the MSS ClinRO. A p-value of less the 0.05 was accepted as significant.

Results

Over the six-month data collection period a total of 228 patients attended the MDT scar clinic. Only those who consented for their responses to be used in the study were included. In total, 57 patients had completed PROMs prior to attending clinic and therefore had data for both PROMs and ClinROs (adult n=25; young person n=11; child [parent proxy] n=21). Of

this total cohort, 18 patients were being seen in the scar clinic for the first time. The remaining patients were follow-ups. Patient demographics are shown in Table 11.

No limitations were placed on the duration of time elapsed since the burn injury took place and whether they were requested to complete a pre-clinic PROMs. The mean time period since injury and review in scar clinic with PROMs and ClinROs was 44.48 months for adults (range 3-396 months), 50 months for those completing the young person scale (range 4-140 months) and 10.1 months for the children's scale (range 2-29 months).

Cohort	Gender M: F: Not stated	Mean age/ years	Ethnicity
Adult n=25	9:16:0	44	White British (19) Asian British – Indian (3) Black – African/Caribbean (2) Asian/British – Pakistani (2)
Young person n=11	4:7:0	14	White British (8) Asian British – Indian (2) Black – African/Caribbean (1)
Child (parent proxy) n=21	14:7:0	3	White British (10) Asian/British – Sri Lankan (3) Asian/ British – Pakistani (2) Asian/British Indian (2) Asian/British – Bangladeshi (1) Other specified: White and Black Caribbean (1) White/Caribbean/Cypriot (1) White/Asian (1)

Table 11 – Patient demographics oof those attending Scar Clinic during the six-month data collection period and who had completed PROMs prior to review.

Within the child cohort, PROMs were completed by the mother, father or guardian – 12:7:3.

Statistical Analysis

Assistance with all statistical analysis was provided by Dr O. Bodger, Swansea University.

The total sample consists of 57 records of patients with scarring resulting from burns. Adults (44%, 25/57) and children (37%, 21/57) make up the largest groups, with a smaller group for young persons (19%, 11/57). The sample is split equally between males (53%, 30/57) and females (47%, 27/57). The three cohorts are, in most ways, quite similar. In terms of gender there appear to be small differences, but the association falls slightly short of the threshold for significance (p=0.083, Chi-Square).

Pearson correlation co-efficient was employed to identify relationships between the global PROM score, the wound/scar dissatisfaction domain of the PROM and the MSS in all patient cohorts separately: adult, young person and child (parent proxy), and grouped. The CARe Burn Scale PROM records patient responses and tabulates these into numerical values whereby the higher score relates to an overall more positive patient outcome. Conversely the MSS ClinRO relies on a lower score affirming a more favourable scar outcome. This results in a negative correlation according to the Pearson correlation co-efficient. The total scores attainable in the PROM and ClinRO with the minimum and maximum results observed correlation with severity (positive or negative) are summarised in Table 12.

Score	Correlation with severity	Min-Max Possible	Min-Max (observed)	Mean (SD)
PROM (adult)	Negative	0-1400	158-1147	643 (252)
PROM (Child)	Negative	11-355	144-355	251 (63)
PROM (Young Person)	Negative	12-660	184-496	326 (102)
Wound/scar dissatisfaction (PROM)	Negative	0-100	0-100	50 (30)
MSS	Positive	6-28	5-25	14 (5)

Table 12 – Maximum and minimum scores attainable in the CARe Burn Scale PROMs and the MSS ClinRO with the maximum and minimum scores observed in the patient cohort. Wound/scar dissatisfaction relates to the CARe Burns Scale sub-domain specifically documenting the patient satisfaction with their current wound/scar outcome. The PROM correlation with severity is negative with a better perceived outcome

Although data was collected by age, all results were combined to elicit trends in the complete cohort of n=57. As the Global PROMs score maximum totals in each group differ (adult /1400, young person /660, child/355) they were standardised and rescaled to run from 0-100 allowing all cohorts to have the same range values.

In the first instance correlations in global PROMS weere reviewed prior to separation into cohorts by age. Wound/scar dissatisfaction (Diss) is a subset of the global PROM and in the combined patient cohort scores there is a high degree of association, a "very strong" correlation (r=0.72 [0.56, 0.82].

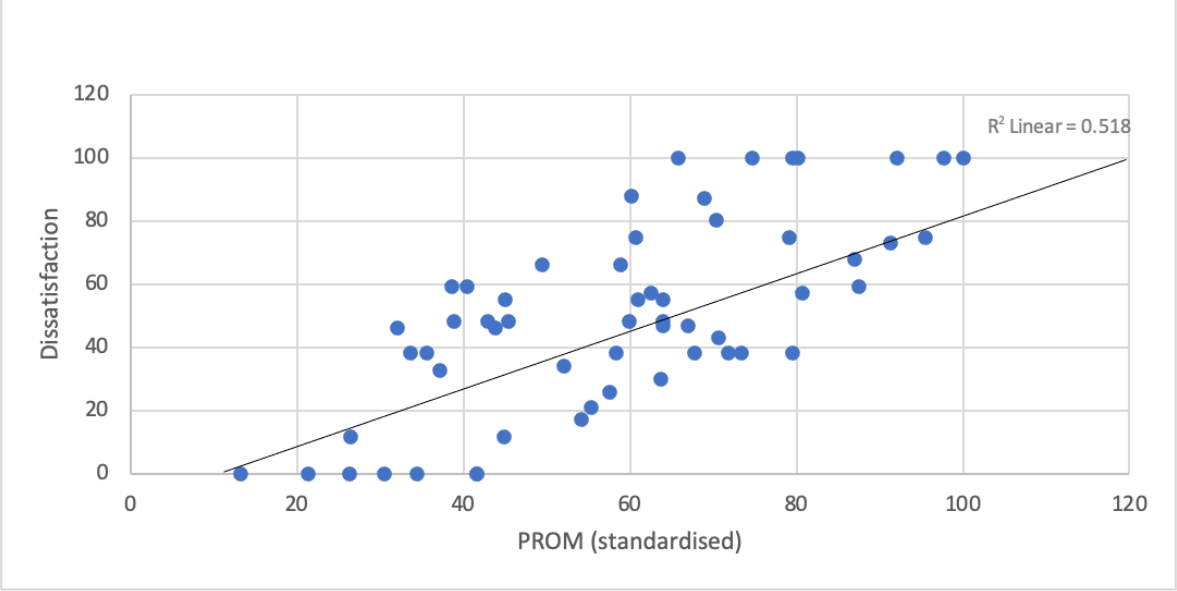


Figure 6 – Scatterplot demonstrating the positive trend in relationship between the Global PROM (x-axis) and the sub-domain of wound/scar dissatisfaction (y-axis) in the combined patient cohort.

Similarly, the VAS is a global assessment component of the MSS which also shows "very strong" correlation to the total MSS (r=0.95 [0.92, 0.97]. The correlation coefficient shows they 'share' over 90% of the same information, with an "Excellent" level of internal consistency (Cronbach's Alpha=0.91).

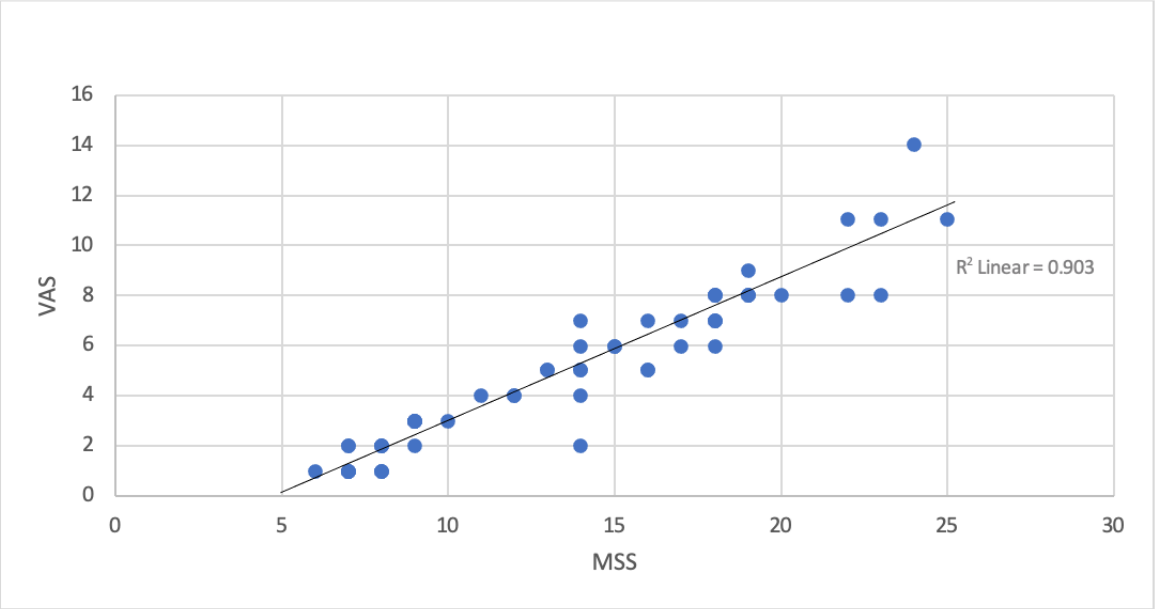


Figure 7 – Scatterplot demonstrating the positive trend in relationship between the VAS – a sub-domain of the total MSS (y-axis) and total MSS (x-axis) in the combined patient cohort.

Initially, results were used to determine the extent to which the MSS and (standardised) global PROMs scores are associated. When considering all cohorts together, there was a highly significant association ($p<0.001$) but a slightly lower level of correlation ($r=-0.59$ [-0.38,-0.73]) but this is still characterised as "strong". As described, the negative sign results from the fact the two measures scale in opposite directions. Next, results were used to determine how well MSS associates with the dissatisfaction scores of all cohorts combined. This association is also "strong", with an only slightly lower correlation coefficient ($r=-0.56$ [-0.34,-0.71]). Additionally, as it was noted the VAS and MSS share such a significant portion of collected information, the cross-correlation between VAS and dissatisfaction was considered. Since MSS and VAS are effectively surrogates there was expected to be a similar association with the dissatisfaction score. The observed correlation is actually slightly higher in VAS alone as thee ClinRO ($r=-0.6$ [-0.4,-0.74]) although an examination of the confidence intervals shows that this difference between the total MSS and the sub-scale of VAS alone is unlikely to be significant.

Adult

In the adult cohort, the correlation between the dissatisfaction score and the global PROM result correlated relatively well (corr =0.708, 50% overlap) suggesting their measurements within the adult group indeed correspond with those perceiving a more favourable scar outcome having a mirrored more favourable global PROM, but it is important to note the global score contains additional useful information in clinical decision making beyond just the scar appearance.

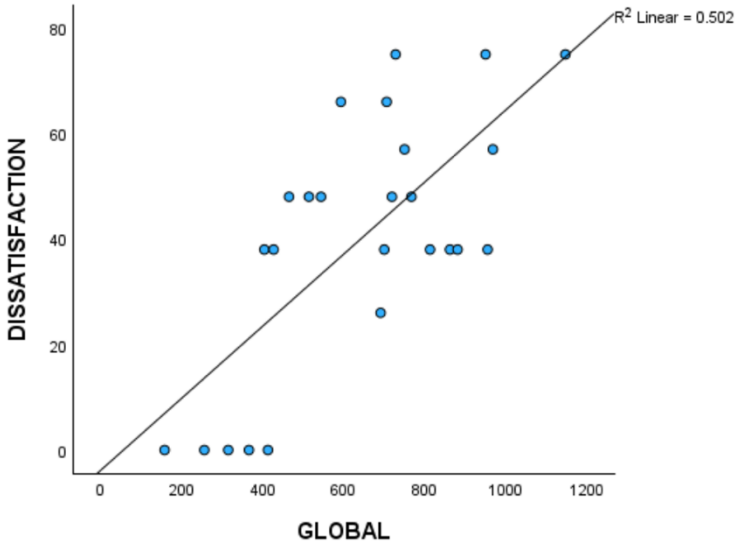


Figure 8 – Scatterplot demonstrating the positive trend in relationship between the Wound/ Scar dissatisfaction [DISSATISFACTION] – a sub-domain of the total MSS (y-axis) and global PROMS [GLOBAL] (x-axis) in the adult patient cohort.

In the adult cohort group there appears to be strong negative correlation between the global MSS and the global PROMs (-0.673, $p<0.001$) Likewise there remains a negative correlation between global MSS and wound/scar dissatisfaction (-0.393, $p=0.052$) suggesting a weak to moderate correlation between the patient and clinician perception of the scar outcome. Summary data for the adult cohort is displayed in Table 13.

		GLOBAL	Dissatisfaction	MSS	VAS
GLOBAL	Pearson Correlation	1	.708**	-.673**	-.691**
	Sig. (2-tailed)		<.001	<.001	<.001
Diss	Pearson Correlation	.708**	1	-.393	-.423*
	Sig. (2-tailed)	<.001		.052	.035
MSS	Pearson Correlation	-.673**	-.393	1	.919**
	Sig. (2-tailed)	<.001	.052		<.001
VAS	Pearson Correlation	-.691**	-.423*	.919**	1
	Sig. (2-tailed)	<.001	.035	<.001	

**. Correlation is significant at the 0.01 level (2-tailed) *p value*
*. Correlation is significant at the 0.05 level (2-tailed) *p value*

Table 13 – Univariable mixed model analysis describing the relationships between total PROMs score (GLOBAL), wound/scar dissatisfaction the sub-domain of the PROM (Diss), the MSS and the VAS in the adult cohort (n=25).

Young person

There are substantial differences seen between the cohort data in the young person and the adult groups. In both groups it is noted that the global PROMs score and the wound/scar dissatisfaction scores are highly correlated however in the young person data set there is less correlation between the MSS and scar dissatisfaction score (-0.283, p = 0.399) showing no significance or evidence of a relationship between the patient perception of the wound/scar dissatisfaction sub-group and the clinician perception on the MSS. Likewise, the MSS against the global PROMS (-0.19, p=0.597) was not significant enough to show evidence of a correlation between the MSS and the global PROMs.

		GLOBAL	Dissatisfaction	MSS	VAS
GLOBAL	Pearson Correlation	1	.776**	-.190	-.410
	Sig. (2-tailed)		.005	.576	.211
Dissatisfaction	Pearson Correlation	.776**	1	-.283	-.399
	Sig. (2-tailed)	.005		.399	.224
MSS	Pearson Correlation	-.190	-.283	1	.937**
	Sig. (2-tailed)	.576	.399		<.001
VAS	Pearson Correlation	-.410	-.399	.937**	1
	Sig. (2-tailed)	.211	.224	<.001	

**. Correlation is significant at the 0.01 level (2-tailed) *p value*
*. Correlation is significant at the 0.05 level (2-tailed) *p value*

Table 14 – Univariable mixed model analysis describing the relationships between total PROMs score (GLOBAL), wound/scar dissatisfaction the sub-domain of the PROM (Diss), the MSS and the VAS in the young person cohort (n=11).

Child

Within the child data set, the pattern of correlations is more similar to that seen within the adult cohort. As with the adult group, there is a strong correlation between the PROMs global score and the sub-group of wound/scar dissatisfaction. In the child group there is a strong correlation noted between the ClinRO MSS and the PROMs sub-group of wound/scar dissatisfaction (-0.723, $p<0.001$) suggesting the clinician assessment of the child's scar relates to that of the parental proxy perception. This is similar to results seen in the adult cohort. There is a weak correlation between the global PROMs and MSS in this subgroup with a p-value negating statistical significance of the result ($r=-0.309$, $p=0.173$).

		GLOBAL	Dissatisfaction	MSS	VAS
GLOBAL	Pearson Correlation	1	.624**	-.309	-.409
	Sig. (2-tailed)		.002	.173	.065
Dissatisfaction	Pearson Correlation	.624**	1	-.723**	-.810**
	Sig. (2-tailed)	.002		<.001	<.001
MSS	Pearson Correlation	-.309	-.723**	1	.942**
	Sig. (2-tailed)	.173	<.001		<.001
VAS	Pearson Correlation	-.409	-.810**	.942**	1
	Sig. (2-tailed)	.065	<.001	<.001	

**. Correlation is significant at the 0.01 level (2-tailed) *p value*
*. Correlation is significant at the 0.05 level (2-tailed) *p value*

Table 15 – Univariable mixed model analysis describing the relationships between total PROMs score (GLOBAL), wound/scar dissatisfaction the sub-domain of the PROM (Diss), the MSS and the VAS in the child (parent proxy) cohort (n=21).

A summary of the resulting correlations between the cohort groups and the outcome measures are tabulated below (Table 16).

Correlation (CI)	Adult	Child	Young Person
PROM vs Diss	0.71 [0.44,0.86]***	0.62 [0.26,0.83]**	0.78 [0.33,0.94]**
MSS vs VAS	0.92 [0.82,0.96]***	0.94 [0.86,0.98]***	0.94 [0.77,0.98]***
MSS vs Diss	0.39 [0,0.68]	0.72 [0.42,0.88]***	0.28 [-0.38,0.76]
VAS vs Diss	0.42 [0.03,0.70]*	0.81 [0.58,0.92]***	0.40 [-0.26,0.81]
MSS vs PROM	0.67 [0.38,0.84]***	0.31 [-0.14,0.65]	0.19 [-0.46,0.71]
VAS vs PROM	0.69 [0.41,0.85]***	0.41 [-0.03,0.72]	0.41 [-0.25,0.81]
***. Correlation is significant at the 0.1% level **. Correlation is significant at the 1% level *. Correlation is significant at the 5% level			

Table 16 –Absolute value of correlations between outcome measures in each cohort group

Discussion

Can PROMs and ClinROs be successfully applied in a burns Scar Clinic setting?

In the SMH MDT it has been shown that PROMs and ClinROs can be successfully applied to the outpatient Scar Clinic setting. Of the 228 patents that attended the scar clinic during the six-month data collection period, all patients had their scars assessed by the same clinician and the ClinRO score recorded using the MSS for the full attending cohort. The same singular researcher was used for the clinician assessment of scar outcome with a view to improve intra-rater reliability. The application of the ClinRO within the clinic setting proved more achievable than the use of a pre-clinic PROM as the latter relied on patients accessing the form and having time for completion prior to assessment. This is reflected in the fact that of the 228 strong cohort attending clinic, only 25% of patients had completed PROMs at time of review. Although the PROM assessment tool request email was sent with an explanation on how their results would be used positively to inform the Scar Clinic interaction, no reminders were sent for completion. Monetary gain was not available to the unit to incentivise PROM completion, which has been demonstrated to improve absolute response rate in paper questionnaires in clinical studies by up to 10% (126). Email

reminders have been shown somewhat effective in improving response rate (127) – a strategy this study would employ in future work.

What additional information does the application of PROMs and ClinROs add to the management of patients in this setting?

The results from the PROMs directed which MDT member opened the consultation. Traditionally within the SMH Scar Clinic, the Burns Consultant or Junior Doctors would commence the dialogue with the patient. Of the 57 patient interactions whereby PROMs had been completed prior to clinic review, 16 of these were opened by the Burns Psychology team. From this, 5 patients were seen by the Burns Psychologists in separate follow-up appointments; all were new referrals. No previously discharged patient required separate re-referral to the Burns Psychology team outside of the MDT Scar Clinic setting. The application of the pre-clinic PROM has gone some way to add depth to the MDT clinic, however without patient feedback from the updated clinic structure it remains unclear if this has had an impact on patient satisfaction regarding the clinic interaction. Formalised patient interviews to gain feedback would be a proposed future direction for the study to further streamline the interaction between patient and MDT members. From discussion within the MDT, there was consensus that the application of the outcome measure tools did in fact add additional information to the clinical interaction that may have been overlooked without them. By allowing a change in weighting of patient interactions between team members according to patient identified need, the MDT felt they were able to spend more time addressing the patient concerns that may have been lost in the previous clinic structure where no outcome measures were employed. The use of the PROM and ClinRO was completed on a single clinical interaction. To understand if the application of the tools have added any additional information pertaining to meeting patient care needs, repeated measures would need to be taken to garner a greater depth of understanding as to whether interventions have improved outcomes. Work has demonstrated that real-time PROMs in burns clinics improve communication channels between patients and clinicians, with

treatment plans being tailored according to patient priorities (128). With a six-month data collection period in the SMH MDT study, this was inadequate to demonstrate progression over time as of the total cohort of patients seen, 18 were reviewed twice in the data collection period. Of these, only 2 patients completed PROMs (and hence had ClinRO also completed). Of these 2 patients, neither repeated the PROMs despite the same email PROMs questionnaire sent prior to their follow-up. Both patients reported not realising the tool would be useful to be completed again to evaluate outcome progression – a downfall in communication between healthcare professional and patient.

From this data set, we see that the MSS and VAS scores are effectively measuring the same underlying construct. This may support the use of less time-consuming metrics by clinicians in assessing the impact of scars. The conclusions on the use of MSS as a surrogate for the PROMs are less clear. This work demonstrates the CARe Burns Scale PROMs are less internally consistent than the clinician scores on the MSS, meaning that the PROMs contain more than simple measures of satisfaction, a not unexpected result.

Is there corelation between the global outcome of the PROMs and ClinRO or between the scar assessment according to the PROM and ClinRO?

In the initial evaluation, all patient cohorts with their PROMs scores were grouped. The association between global PROMs and MSS was highly significant ($p<0.001$) with a strong level of correlation ($r=-0.59$ [-0.38,-0.73]). When determining the association and correlation between the MSS ClinRO and the wound/scar dissatisfaction subgroup of the PROM, the correlation co-efficient level remains high, but slightly lower than global PROMs ($r=-0.56$ [-0.34,-0.71]). Given the strong correlation between the wound/scar dissatisfaction and the ClinRO, this suggests the tools may in fact be capturing the same information and the patient perception of their scar matches that of the clinician, posing the notion this particular ClinRO is of limited use in the scar assessment when the CARe burns scale has been applied by the patient. Were the tools measuring exactly the same outcomes,

the correlations may have been higher. As this is not the case in this study, there may still be features of the patient's wound or scar captured by one measurement tool and missed by the other. This study identifies the need to compare and correlate alternative ClinROs to the CARe Burn Scale to identify if this PROM alone is sufficient in this clinic setting, therefore negating the requirement for a ClinRO.

Extrapolating from the literature, it was hypothesis there may be a correlation between the global PROM and the ClinRO (124). Despite the CARe burn scale PROM having a broader set of domains beyond scar appearance, there was a strong correlation between global PROMs vs MSS when the cohort was grouped. This may be accounted for by some of the other PROMs domains beyond the wound/scar dissatisfaction sub-group being influenced by the scar appearance, such as physical wellbeing and positive growth. There was a less strong correlation seen between the grouped ClinRO and PROM sub-domain of wound/scar dissatisfaction. Work has identified the broad notion of 'good wound healing' being the most important measure to patients and related to not only scar quality but also to function (84). Similarly, Edgar et al and Meirte found that the scar-related outcomes were deemed the most important measure to the burns professionals (129, 130). These conclusions are not supported by this study, as a higher level of correlation between the MSS the wound/scar sub-domain of the PROM and perhaps the global PROM, would be expected if the scar is indeed the most important outcome measure to all stakeholders.

With the cohorts grouped, the somewhat strong correlation between the clinician perspective and the patient perspective of the wound/scar PROM sub-domain suggests the MSS is an acceptable tool in capturing an agreed scar outcome. The results of this study perhaps negates the role of this particular ClinRO when the CARe Burn Scale is used as the PROM as they measures may be capturing the same data in relation to the scar assessment. Importantly however, medical practitioners must consider additional factors, such as

patient's expectations of their scar healing, their clinical journey or the anatomical area burnt that may impact the global PROM and lead to discordance in the clinician perspective of the overall burn outcome if practitioners are using scar appearance as their "endpoint" in burn recovery.

Although surgical intervention in the management of the burn may be a factor affecting both the patient and clinician perceived outcome, recent work in paediatric burns found no statistical difference in the parental perceived outcome of their child's scar whether they were managed with hydrosurgical debridement or conservatively with dressings alone (131). The specific nature of the burn management has not been explored in this study, however it is highlighted as an important factor to consider in future work.

The dual utilisation of PROMs and ClinROs has generated a body of literature in rehabilitation post lower limb trauma not seen in the burns setting. Bily et al identified the associations between PROMs and ClinROs in those patients recovering from traumatic lower limb injuries, observing low to average correlations between the outcome measures across a cohort of 315 patients (132). It has been proposed that measuring PROMs and ClinROs together regularly allows the clinician to evaluate changes in the patients' performance status that are caused by treatment effect allowing a greater depth of assessment with clinician and patient centred tools (133, 134). In light of this study in the MDT Scar Clinic demonstrating preliminary relationships between the outcome measures regardless of the duration of time elapsed between injury, implementation of the tools in the acute and long-term settings may be prudent to assess any changes in scar perception over time.

Relationships between the CARe Burn Scale, the wound/scar dissatisfaction sub-scale and the MSS become weaker when the data is analysed at the individual cohort level. Greater

correlation between the global PROM, dissatisfaction sub-scale and the MSS is seen in the adult and child groups (whereby a parent or guardian has completed the latter questionnaire), than in the young person group. This may be due to the adult and child scales being completed by an adult. Within the child group, the correlation between the wound/scar dissatisfaction is stronger with the MSS than the global PROM. It is accepted that the global PROM brings additional facets beyond the wound itself, but it is important to note the particularly subjective nature of this PROM as it is completed by the parental proxy on the child's behalf. Additional factors relating to the injury such as parental guilt or feelings of blame have been noted in the literature to have an impact on parental perception of their child's scars (135). Through thematic analysis of family interviews, guilt ruminations, blame attribution and shame were pivotal factors across the lifespan of burn survivor's families (136). The literature suggests there can be difficulties with re-establishing familial emotional connections with the burnt paediatric patient, and sibling jealously as the burnt child is reintegrated into the family unit (137). Work by De Young et al found up to 25% of parents had a probable post-traumatic stress disorder diagnosis after a burn accident affecting their child up to six-month post injury. After this time, this reduced to approximately 5% of parents (138). Within our study cohort for children, the mean time passed since outcome measure application was 10.1 months (range 2-19 months) identifying some parents to be potentially at risk of significant emotional distress at time of questionnaire completion, perhaps negatively impacting their PROMs results.

The sample size of n=11 for young patients was deemed too limited to garner any statistically significant results on analysis, therefore results from this cohort should be considered hypothesis forming. In the raw data, overall a more favourable scar outcome was documented by the clinician than by the young person, when evaluating the results of both the global PROM and the dissatisfaction sub-scale. Also, the young person cohort had lower overall scores in all PROMs domains compared to the adult cohort group. Results of this

work in relation to the young person's data corroborates some of the published literature examining this age group. Evidence exists through a study of 531 participants aged 10-19 years (M: F 213:318), that younger adolescents had higher body image dissatisfaction than their peers (139). In Partridge's stages of burn recovery discussed at the American Burn Association conference in Chicago (2005) it was suggested adolescents may struggle to transition from the "pre-burn self" concept to the "permanently scarred", finding it difficult to adjust their identity (140). Published literature on adolescent burns survivors is mixed, as other work shows that patient perception of social acceptance and self-image in adolescence was significantly higher in this age group when compared to their normative counterparts (141).

The global pandemic may have impacted the overall patient perception of their burn outcome as domains relating to friend support, family and intimacy potentially reduced during this period. This may have influenced an overall less favourable PROMs assessment, with scores dropped precipitously due to the isolation the patient had to undertake thus causing a hidden bias towards a more negative PROM outcome. Had patients not been required to stay at home and isolate, a more positive overall global outcome may have been achieved. With the ClinRO being unaffected by subjective influences relating to self-isolation, a repeat study with unrestricted social measures could conceivably lead to a change in outcome measure correlations.

Limitations

The small sample size and lack of reminders sent for PROMs completion are limitations in this study. The results of this study were not stratified according to the significant variables seen in burn mechanism, TBSA, anatomical area involved, Fitzpatrick skin type, surgical vs conservative management, wound healing time or patient co-morbidities. Future direction for

the cohort group within the SMH Scar Clinic data set would be investigating if the relationships between the PROM and ClinRO correlated with these heterogenous variables seen in burn injuries.

No limitations were placed on the time since the burn injury took place and whether patients were invited to complete a pre-clinic PROMs. 396 months since burn and outcome measure application was the greatest time elapsed. Work in alternative clinical settings has found that PROMs show a greater improvement in the acute recovery phase where ClinROs took significantly longer to show improvement (142). Results of this work represent a single snapshot in time and do not account for changes that could be seen on multiple reviews and outcome measure repeats. Both longer surveillance periods and multiple assessment time points could produce different results. Should this study be repeated, PROMs and ClinROs should be collected at pre-determined time points through recovery to elicit patient and clinician priorities at different stages of healing. This may assist in future clinical decision making in burn patient scars.

The exclusion of patients without access to an electronic device to complete the PROMs, or those with a limited understanding of written English, may have accounted for the small sample size. Giving patients access to an iPad while in the waiting room in order to complete their PROMs may address this in the future, however through increased sanitisation experienced in the COVID-19 pandemic and reduced face-to face consultations, this was not feasible at the time of data collection.

Conclusions

This is the first reported study of its kind to utilise both PROMs and ClinROs simultaneously within the burns clinic setting, demonstrating both its feasibility and

usefulness in widening the MDTs understanding of patient specific priorities and opening channels of discussion between clinician and healthcare professional.

In summary, there do appear to be relatively meaningful differences in correlations between the CARe Burns Scale PROMs and the MSS ClinRO within the separate cohorts. We can only speculate on the reason for this, but possible explanations may be the differing nature of injuries between cohorts, the different perspectives of the raters in each case and the differences in the way the scores are calculated for each group. Although the correlation seen between the ClinRO and the wound/scar domain of the PROM suggests the PROM alone may be acceptable in evaluating scar outcome, further work comparing alternative clinician reported outcome measures is required. Importantly, the study suggests when used in combination, the patient reported, and clinician reported outcome measures contribute to the collection of complementary information allowing for patients and practitioners to embarked on shared decision making when planning relevant future care.

Chapter 4 – Investigating correlations between the Patient Reported Outcome Measure and Clinician Reported Outcome Measure in relation to the burn injury details

Introduction

Survivors of burn injuries are at risk of experiencing multifaceted biopsychosocial complicators in their future post-acute trauma recovery. These problems can range from body image perception, scar cosmesis, social interactions, intimate relationships, employment challenges and an overall reduction in quality of life (143-146). In the development of PROMs across clinical practice, Brédart et al clarify the importance of utilising qualitative research methods in identifying domains of relevance (147). Regarding burns-specific PROMs, Griffiths et al stress the requirement for these measures to represent the key factors important to the patient cohort that are unique to this population \page. Historically outcome measures in clinical practice have related to clinician observations, while the patient perspective of their disease state, the severity of their symptoms or treatment related complications, have been somewhat undervalued as a result of the antiquated belief that patient reporting is unreliable (148). When managing the chronic disease state of scarring post burn, the long-term ramifications of the disease burden can only truly be interpreted by each patient on an individual basis. ClinROs in burns scars can direct clinicians to address modifiable states of the disease, however, if the clinician's treatments reflect a domain in the PROM that is of little value to the patient, the patient may have "improved" from the clinician's perspective, but not in a way that is meaningful to the patient. It is the relationship between the ClinRO and PROM in burn scarring that therefore warrants further investigation.

The relationship between PROMs and ClinROs have been investigated within multiple clinical specialities. Jacobi et al noted when managing patients with spinocerebellar ataxia

that there were factors not covered within their validated patient specific PROMs and not captured within clinician observed endpoints, that have significant impact on patient overall wellbeing (149). It was noted that those patients struggling with fatigue had worse PROMs despite similar ClinROs compared to a patient without fatigue. Similarly, depressive symptoms, which do not manifest as severe enough to score on clinician outcome measures, have a relationship with poorer PROMs (150-152). It has also been commented that this discordance may be down to "hidden domains" that cannot be captured through current PROMs or ClinROs but have a significant impact on patient function (153,154).

The discordance between PROMs and ClinROs have been of particular interest within orthopaedic research – for example in the investigation of improving PROMs post-surgical intervention in rotator cuff injuries. It has been noted that poor psychological function pre-operatively was associated with limited improvement in PROMs despite objectively mild improvements in functionality when ClinROs were implemented (155, 156). Similarly mental health was significantly associated with negative PROMs in the domains related to pain or perceived shoulder function in discordance with improved ClinRO post operatively (57, 158). It must be acknowledged however that the ClinROs being compared in these settings were not designed to probe psychological outcomes, but rather the functional outcomes of joint range and activities of daily living. It may be that the 'hidden domains' representing discordance between the PROMs and ClinROs in these studies are simply the lack of the chosen clinician outcome measure being able to consider the psychological sequalae of the disease being measured.

The majority of research related to burns has focused on hard endpoints such as mortality, along with social factors pertaining to hospital stay, care costs to health services and patients

or time taken to return to work. The multidimensional lifetime coping of burns survivors means that solidly defined "endpoints in care" may not be appropriate – hence the move towards burns research employing PROMs specifically designed to investigate the psychological ramifications of a burn (159, 160). Despite this ClinROs remain readily employed and, unlike in alternative clinical settings, there is little evidence investigating the potential discordance between these ClinROs and PROMs in burns care. In such a complex injury process in both the acute and long-term settings, it would be remiss to presume that there is (i) no relationship between the PROMs and ClinROs in burns care outcomes, (ii) there is no discordance between burn patient specific PROMs and ClinROs and (iii) the combination of a burn specific PROM and ClinRO capture all the key domains of importance to overall patient care.

In Chapter 3 it was suggested that there is a relationship between the results of the CARe Burn Scale PROM and the MSS ClinRO across all examined patient cohorts: adult, young person and child (parent proxy). This preliminary work has identified there is a range in the strength of the relationship between the clinician perceived scar outcome and the patient perceived scar outcome across all groups. The use of both PROMs and ClinROs in the MDT Scar Clinic setting have assisted in the team's understanding of patient specific priorities and opening channels of discussion between patient, clinician and healthcare professional, however the relatively meaningful differences in correlations between the CARe Burn Scale PROMs and MSS ClinRO between cohorts warrants further investigation. Following a review of the literature pertaining to burn factors that may impact the post injury PROM, it was found that male gender, younger age, white collar profession, smaller affected TBSA and reduced TBSA of full thickness burn, less post burn puritis, reduced time to return to work or school and improved sleep quality had an overall better patient reported outcome (84, 161, 162). Regarding the literature related to predictors informing a more favourable clinician

reported outcome measure in burns scarring, it was found that a smaller TBSA affected, and more superficial wound depth were the most significant factors (11, 50, 163, 164)There were no documented studies investigating the correlations between patient perception and clinician perception of the above variables utilising a burn-specific PROM, which addressed domains beyond the burn scar appearance, and an additional ClinRO tool. This study therefore sets out to be hypothesis forming, proposing there is discordance in the correlations between clinician perception and patient perception of their scar and overall outcomes which may be related to the heterogeneity of the burn injury. With the existing literature documenting that TBSA and wound depth are key factors influencing both PROMs and ClinROs in burns care, these are the measures that will be used as the starting point in exploring the discordance in strength of correlations between the outcome measures.

Research Question

Are there any trends in the patient's burn injury that correlate with the chosen Patient Reported Outcome Measure and the Clinician Reported Outcome Measure?

Methods

All necessary approvals were obtained to conduct the study – the work was deemed to be a Quality Improvement project by the Trust's Research and Innovations Committee, therefore no additional ethical approvals were required.

Study Design and participants

This study represents a retrospective cohort analysis of patients who attended the SMH Scar Clinic between May – November 2021 and completed the CARe Burns Scale PROMs prior to

assessment and had the MSS ClinRO applied at the time of clinic. This is the same patient cohort as described in Chapter 2 with the same inclusion criteria (Table 10).

Data collection

Existing quantitative data from the consenting patients completing the CARe Burns Scale PROMs and had the clinician scored MSS during the Scar Clinic were selected from the NHS server along with their demographics of age, gender and date of injury. Baseline characteristics were derived from the International Burn Injury Database (iBID) and the electronic clinical encounter documenting system employed by Buckinghamshire NHS Trust, Evolve. These characteristics reflected those highlighted in the literature review, namely % TBSA affected and % full thickness burns. Additionally, anatomical site(s) affected, burn mechanism, surgical management and time to healing were also documented.

Data analysis method

All data analyses were performed using IBS SPSS 29. The Pearson correlation co-efficient equation was used to measure the linear correlation between the %TBSA burn and the global CARe Burn Scale PROM along with the %TBSA burn against the MSS ClinRO in each patient cohort. As a separate evaluation the Pearson correlation co-efficient was used to measure the correlation between the %TBSA affected and the sub-group of wound/scar dissatisfaction in all cohorts, with the MSS ClinRO. A p-value of less the 0.05 was accepted as significant.

The Kruskal-Wallis H test (continuous variables) and the Chi-Square tests (categorical variables) were used to compare the characteristics of the patients in relation to burn mechanism and anatomical area affected.

Results

The area defined as partial thickness (PT), full thickness (FT) and mixed depth varied according to clinician assessment and documentation in the acute burn setting therefore the first recorded initial assessment results were used for all patients for consistency and are used to assist in observation only. Likewise, time to healing documentation varied from a fixed date since time of injury to an estimate of the number of weeks taken to heal according to clinic records, therefore this exact value for the patient cohorts is intrinsically unreliable. Due to the retrospective nature of the data collection method, the only reliable values recorded for every patient were %TBSA burned, anatomical location involved and mechanism of injury.

The total sample consisted of 57 records of patients with scarring resulting from burns. Adults (44%, 25/57) and children (37%, 21/57) made up the largest groups, with a smaller group of young persons (19%, 11/57). The sample was split equally between males (53%, 30/57) and females (47%, 27/57). The three cohorts are, in most ways, quite similar. In terms of gender there appear to be small differences, but the association falls slightly short of the threshold for significance ($p=0.083$, Chi-Square). Patient details relating to the TBSA of the burn, burn depth, burn mechanism, anatomical site affected and documented time to healing are summarised in Table 17.

	TBSA %	Depth	Mechanism	Site	Time to healing
Adult n=25	<5 n=15 5-10 n=6 >10 n=4	FT n=4 PT n=13 Mixed n=8	Flame n=14 Scald n=6 Contact n=2 Chemical n=1 Electrical n=2	Head/face/neck n=6 Torso n=4 Hand n=3 Upper limb (excluding hand) n=2 Lower limb n=8 Genitalia n=1 Multiple sites n=1	Within 3 weeks n=8 >3 weeks n=17
Young person n=11	<5 n=8 5-10 n=2 >10 n=1	FT n=2 PT n=5 Mixed n=4	Flame n=7 Scald n=3 Contact n=1	Head/face/neck n=3 Torso n=2 Hand n=1 Upper limb (excluding hand) n=2 Lower limb n=2 Multiple sites n= 1	Within 3 weeks n=4 >3 weeks n=7
Child n=21	<5 n= 16 5-10 n=4 >10 n=1	FT n=2 PT n=17 Mixed n=2	Scald n=18 Contact n=2 Friction n=1	Head/face/neck n=2 Torso n=8 Upper limb (excluding hand) n=1 Hand n=3 Lower limb n=3 Multiple sites n=4	Within 3 weeks n=16 >3 weeks n=5

Table 17 – Details documented in iBID and Evolve of the patient cohort relating to %TBSA bunt, depth of burn (FT = full thickness; PT = partial thickness), the anatomical site of the burn and first documented time the burn was deemed to be healed.

The area affected also showed no difference between cohorts (p=0.188, Kruskal-Wallis) or in terms of the proportion of burns affecting the head/face/neck or hands (p=0.828 and p=0.786 respectively, Chi-Square). However, in the mechanism of injury, there were significant

differences between groups (p<0.001, Chi-Square), with almost all burns to children arising from scalds (86%, 18/21) while adult burns are mostly from flame injuries (56%, 14/25) with only a quarter being scalds (24%, 6/25).

The burn TBSA varied from a minimum of 1% to a maximum of 60% with median (IQR) of 3% (6). Only a small proportion (14%, 8/57) had coverage equal to or greater than 10% (seen as n=6 in>10% TBSA and n=2 in the 5-10% TBSA group).

When all ages of the patient cohort are grouped, the majority of burns were caused by scalding (47%, 27/57) and flame (37%, 21/57), with only a handful of cases of contact burns (5), electrical (2), chemical (1) and friction (1). Within the sample, about a fifth (19%, 11/57) of burns affect the face or head and only one in seven (14%, 8/57) affect the hands.

In relation to the patient reported and clinician reported outcome measures and correlations with the variables in the patient journey, the cohort size was too small to draw statistical conclusions in relation to the anatomical area affected given the heterogeneity of injury location. In relation to %TBSA, when all cohorts are grouped there is moderate negative correlation in global PROMS (-0.403, p=0.002) and wound/scar dissatisfaction (-0.325, p=0.014) suggesting, as the %TBSA involved increases, the patient perception of their outcome worsens. Likewise the positive correlation between the MSS ClinRO and %TBSA (0.449, p=<0.001) indicates that, as the surface area involved in the burn increases, so does the clinician perception of a poor scar outcome. However when the cohorts are split according to age group and therefore the CARe Burns Scale PROMS completed these relationships weaken. In the adult cohort a statistically significant relationship is seen between TBSA and global PROMS (-0.407, p=0.018) and TBSA with MSS (0.421, p=0.036), however not in the wound/scar dissatisfaction subscale. Within the child cohort the only result deemed statistically significant was the correlation seen between wound/scar

dissatisfaction and TBSA (0.496, p=0.032). No correlations were statistically significant within the young person cohort. There were no missing data on the reporting of %TBSA and anatomical area affected (Table 18).

			Outcome measure		
			Global PROM	**Wound/Scar dissatisfaction PROM subscale**	**MSS ClinRO**
Adult n=25	**%TBSA**	Pearson Correlation	-.470*	-.366	.421*
		Sig. (2-tailed) *[p value]*	.018	.072	.036
Young person n=11		Pearson Correlation	-.233	-.126	.224
		Sig. (2-tailed) *[p value]*	.490	.713	.507
Child n=21		Pearson Correlation	-.374	-.469*	.398
		Sig. (2-tailed) *[p value]*	.095	.032	.074
Total cohort n=57		Pearson Correlation	-.403**	-.325*	.449**
		Sig. (2-tailed) *[p value]*	.002	.014	<.001

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Table 18 – Correlation between %TBSA against Global PROM, Wound/Scar Dissatisfaction sub-scale of the CARE Burns Scale and the MSS ClinRO.

Discussion

This single centre retrospective cohort analysis investigated the correlations seen between the %TBSA burn and the patient perception of their global outcome and wound/scar dissatisfaction in conjunction with the clinician observed outcome. This was due to the TBSA being the only consistently documented assessment measure. Taking the cohort of n=57 as a whole, there was a statistically significant moderate correlation between burn TBSA and both the PROM and ClinRO. This suggests the TBSA may act as predictor for both patient and clinician perceived outcome after a burn. Given the literature, there was the expectation that this correlation would be stronger (11, 50, 163, 164). This was not the case in this study – being only moderate. TBSA and burn depth appear to have a significant impact on patient reported outcomes in relation to post burn puritis (84, 165). Although puritis is not a domain captured within the outcome tools this study used it could explain why there was a correlation between the PROMS representing a less favourable outcome as TBSA increased.

It was anticipated that the values of the correlations between the PROM and ClinRO in this study relating to TBSA would be more closely related. Taking the total cohort, there was a stronger correlation between the MSS and the TBSA than there was with the wound/scar dissatisfaction subgroup of the PROM. A suggested explanation for this is that the clinician knowledge of the TBSA influences their perception of the scar outcome more readily than the patient might. There is potential risk that the clinician may assess the scar outcome to be less favourable if the original TBSA affected was greater and may suggest treatments to the patient that would improve the ClinRO but add little value to the PROM.

Within the young person cohort no correlations between the TBSA and outcome measures were statistically significant, likely due to the small sample size. In this cohort, the mean time elapsed between initial burn and review in the Scar Clinic with these outcome measures

was 56 months. Considering the patient cohort age on data capture is between 8-17, many patients will have been in infancy when the initial injury occurred. In Partridge's stages of burn recovery discussed at the American Burn Association conference in Chicago (2005) it was suggested adolescents may struggle to transition from the "pre-burn self" concept to the "permanently scarred", finding it difficult to adjust their identity (140). TBSA may therefore be less relevant to this cohort group with alternative comparators such as visible scarring (i.e. to the head and neck) having a stronger correlation to the wound/scar dissatisfaction subgroup or even the global PROMs.

During this study, the time between acute injury and patient review with these outcome measures ranged from 2 months to 396 months with the average time being 40.6 months. Studies utilising the POSAS tool as clinician and patient assessment of scar outcome have shown an improvement in both parties perception of scar quality over a 12-month period with assessments at 3 and 6 months (11). Extrapolating from larger sample sized studies suggests the data in this study would be more representative of mature scars and may favour a more positive outcome assessment than may have been the case had these patients been assessed more acutely after their burn. It is possible that the correlations between scar outcome and TBSA may be stronger in both the clinician and patient assessment while the burn scar remains more active during the maturation phase. Should this study be expanded, time points for the application of burn outcome measure need to be established: 3-, 6-, 12- and 24-months post injury would be justifiable to reflect the existing body of literature investigating the long-term trends in outcome measures after burn injury. The CARe Burn Scale PROM has multiple sub-groups making up the global assessment, of which wound/scar dissatisfaction is just one. The moderate correlation of the wound/scar dissatisfaction sub-group and the TBSA confirms there is a relationship to an extent, reflected by the similar correlation with the MSS, however additional interest would lie in whether correlations manifest to a greater or lesser extent when comparing the TBSA to alternative subgroups such as 'work'. Studies

completed in South Korea reviewing 100 burn patients reported in their cohort the greatest impact on patient perceived outcome was related to the increased time taken to return to work, followed by the appearance of the scar (166) therefore subsequent data collection in the expansion of this study would elucidate whether this finding was reflected within the UK cohort. This may add to the body of evidence to be used when predicting burn outcomes over time; a resource which would assist the clinical team in supporting their patients.

For the purpose of this study, correlations in outcome measures were not assessed according to gender. Female gender has been shown to be a predictor of a more negative patient perception of burn outcome in multiple studies (167, 168). Given the equal distribution of male and female patients in the total cohort, the results of correlations between the TBSA and outcome scales in this study are unlikely to be biased according to gender.

Regarding the burn mechanism, our study identified the majority of burns in the adult population were flame injuries where in children this was scalds. This corroborates the general consensus regarding burn aetiology found in multiple studies (2, 169, 170).

During the retrospective data collection period, TBSA and anatomical location were the only variables in the patient burn journey that were reliably recorded. Additional data was collected where available. This included: acute burn management, surgeries (number and type), dressings, healing complications, co-morbidities including pre-morbid mental state and pressure garment use. The significant amount of missing data meant these results lent themselves to anecdotal commentary only in relation to the patient PROM and ClinRO. On expansion of this study proposed as future work, these domains should commence being

documented consistently as the results may add context and granularity to future evaluation studies investigating relationships between outcome measures and the patient's clinical journey. In addition, the length of hospital stay would be a prudent record given the body of evidence indicating this factor is a predictor for scar outcome (163).

Observational trends were noticed within the data relating to those patients that had a less favourable PROM. It was found that adult patients with a lower limb burn generally had a less favourable PROM. This observation is supported by the literature. It has been demonstrated burns to the lower limb have increased morbidity in the form of DVT and PE in the acute setting but also long-term disabilities resulting from oedema and infections (171-173). Taking lessons from other traumatic lower limb injuries such as open fractures, it has been hypothesised that improved objective outcome measures in strength and balance would mirror the patient's perception of their recovery. A recent randomised multicentre study found that, despite good ClinROs and low complication rates, there was a significant level of patient reported disability through the first 12 months post injury (174). It has been postulated that patient concerns over strength and proprioception of the injured limb may contribute to negative patient reported experiences (175), a phenomenon that also may be seen in lower limb burns. Burn specific rehabilitation research focusing on patients with lower limb burns >40%TBSA have found this cohort of patients to have comparative muscular weakness, limited balance and reduced mobility levels when compared to non-burned patients at 16- and 24-weeks post burn injury (176). Addressing this finding in patients with lower extremity burns, Özkhal et al report that gait training should be added to early rehabilitation programmes for lower limb burns, finding this intervention reduces pain severity and increases gait velocity. They also found the addition of treadmill training over traditional overground gait training had the added benefit for reducing kinesiophobia (177). Although no conclusions can be drawn from our study as to why we observed a less

favourable PROM in the adult patient cohort with lower limb burns, it highlights to practitioners the long-term risks associated with these injuries and perhaps can inform future rehabilitation processes within the department.

A further observation noted was within the child cohort. Of those patients presenting with a less favourable global PROM, the most common shared variable was that two thirds of these patients had undergone hydrosurgical debridement and wound coverage with a biosynthetic dressing (Biobrane). This observation does not corroborate the current published literature. Work investigating the use of chlorhexidine cleansing and silver dressings versus hydrosurgical debridement of paediatrric burns found that there was no statistically significant difference observed in the parental reported outcome relating to long term scarring. In that study, the BBSIP PROM was used (131). Further investigation within our cohort is warranted to determine if there is any statistical significance in the parental perceived scar outcome using the CARe Burn Scale PROM relating to conservative or hydrosurgical management of the paediatric burn.

Limitations

There was no missing data in the documentation of the burn TBSA. Unfortunately, for additional variables of interest that would potentially have a relationship with the wound/scar dissatisfaction subscale and the MSS ClinRO such as the burn depth and the time to healing, there was missing data and unreliable documentation. A key limitation when trying to retrospectively explore multiple variables is the quality of record keeping, for example the exact date of wound healing of a burn is hard to define and rarely recorded accurately. Equally, a failed SSG may be partial or more rarely, complete, therefore complications in the

wound healing process may not be accurately represented. The quality of the patient record must therefore be declared as a confounding factor in this study.

A significant limitation to this work was the inability to study all factors associated with scar quality that had been highlighted in the literature and may well have had a correlation with the PROM and ClinRO. There may have been variables within the burn scar formation that had a stronger correlation with the outcome measures than TBSA and could be investigated further as a potential predictor for burn scar outcomes.

Finally the cohort size was small – particularly when separated into age groups. This somewhat limited the strength of the statistical analysis that could be performed This was a retrospective study with the cohort fixed to those patients that completed the CARe Burns Scale PROMs and had the MSS ClinRO during the data collection period.

Future study design

Given the hypothesis generating nature of this study, if time and resources permitted, these provisional findings would have been expanded. Future research questions can be generated to explore which other variables in the burn injury may or may not correlate with the outcome measures. Power calculations show that a sample size of 150 patients matched on gender and evenly divided across the three age groups would give sufficient strength to analytics pertaining to confirming the relationship between TBSA and the outcome measures used in this study. Additionally, the increased sample size would allow for an exploration of alternative variables raised from the literature search that may influence predicted outcomes

in both patient and clinician measures. These variables would include the anatomical location of the burn and the length of hospital stay as these variables are not subjective.

Over a 6-month data collection period, 228 patients were reviewed in the Scar Clinic but only 57 had completed PROMs. Overcoming the difficulty in study recruitment would require either an increased data collection time frame, or expanding the study to be multicentre in order to meet the proposed cohort number.

This study has found that missing data and unreliable documentation of variables, including burn depth on acute presentation and time to healing, are factors that need to be addressed should the study move forward. Standardised documentation to be completed by all assessing healthcare professionals at pre-determined time points during patient treatment would aid ease and reliability of data collection in conjunction with repeated patient and clinician reported outcome measures to document cohort trends over time.

Conclusion

This study is an exploratory analysis set to be hypothesis generating for future work. Primarily it is believed that similarities between patient burn injuries may lead to similarities in the resulting patient reported and clinician reported outcome measures however it is accepted that there is heterogeneity of the injury mechanism, recovery and patient co-morbidities. It is these factors that risk any similarities in PROMs and ClinROs being coincidental, however would warrant further investigation to determine if there is a predictive

indicator that may lead to a less favourable PROM and perhaps alert clinical teams to act accordingly.

In conclusion this study supports the existing evidence in literature that TBSA of a burn does correlate with patient and clinician reported outcome measures whereby the greater the area involved, the less favourable the perceived outcome, however the weakness in correlation may be accounted for by more than simply the small sample size. The expectation that there would be a strong correlation between the scar assessment and the TBSA has not been met, warranting further investigation into the factors relating to a patient's burn journey that may have a greater impact on both patient and clinician reported outcome measures in the post burn setting.

Chapter 5 – Understanding the role of patient liability in adult burn injury recovery

Introduction

Outcome measures can assist with understanding the patient perception of their burn injury. ClinROs, although informative from the clinician perspective of intervention success, may not influence the PROM if the domain of treatment was not deemed important to the patient (178). In fact, clinician intervention based on poor ClinROs in alternative clinical settings has been shown to lead to worsening the patient's perceived outcomes and disrupting the positive growth post-trauma the patient may have made (179-181). Burn injury and recovery is a complex and multifaceted journey. Mechanism of injury, treatments and recovery is heterogenous. Through rigorous construction and validation of PROM tools, clinicians can apply measures to determine patient recovery and identify areas for development to improve their PROM, although there remains the potential for outcomes important to the patient to be underrepresented or not measured at all. It is important to recognise there are factors not formally measured which may be contributing to the positive patient recovery and their overall perceived outcome after burn injury.

Understanding and interpreting PROMs within burns scar care can assist the clinician in supporting the patient to engage with "Post-Traumatic Growth" (PTG). The completion of PROMs allows the patient to reflect upon their previous, present and potential future health status and empowers them to raise concerns with clinicians that may be impeding their trajectory to achieving personal goals. Joseph et al, building on the PTG theory presented by Tedeschi and Calhoun, developed the Change in Outlook questionnaire post major disaster, and since then, the area of PTG has become increasingly of interest across other clinical disciplines such as cancer, multiple sclerosis, HIV and heart disease (183-192).

Considering PGT within burns patients, Patterson et al first drew attention to the potential for understanding positive growth rather than adopting the prior more conventional deficit model, where only negative emotions were investigated (184). They report the acceptance of "self" forms a key pillar in PTG in burns patients, which tends to stem from rumination and reflection on the injury. Others stipulate that the rumination can result in "psychological shrinkage" and disconnection from the outside word (193, 194).

Through semi-structured interviews involving burns patients, other domains of interest have been identified that compliment burns specific PROMs and assist the clinical team in understanding how a patient copes with life after a major burn, such as their future employment success, educational achievement and forming long term relationships (191, 192, 195, 196). Indeed Lau and Van Niekerk describe personal growth in burn patients, beyond the pre-trauma levels, and report patients experiencing changes in their domains of perspective towards "self" (195).

A 2018 systematic review synthesised feelings of guilt, blame and shame associated with burn injuries in the recovery stages, noting these negative emotional sequelae could be targets for psychological intervention to avoid complications such as Post-Traumatic Stress Disorder (PTSD) (136). Patterson and Tengvall found that both avoidance and wishful thinking were deemed negative emotional responses to burns trauma and were also associated with a higher incidence of PTSD and the use of avoidance as a coping mechanism related to poor overall psychological outcomes (197-199). Conversely, others have identified personality traits such as extraversion and optimism led to more positive psychological outcomes (178). Although there is literature investigating relationships between positive and negative emotional associations relating to positive growth post adult burn trauma, there is a dearth in understanding the impact of patient liability after injury.

DeGood and Kiernan found that in patients with chronic pain, their acceptance of their condition was more positive when they felt they were liable for their own condition as opposed to a third party (200). This work aims to investigate, through the descriptive phenomenology method, whether the patient's own liability in their burn injury may have influenced their positive growth after trauma. Patient liability has not been investigated in the context of burns trauma before, therefore findings within this study may add to the evidence base for future support of patients in the post-burn context.

Methods

This study utilised a descriptive phenomenology methodology using Colaizzi's method of data analysis (200). Phenomenological research focuses on exploring and understanding individuals' lived experiences. It seeks to describe and analyse the essence of those experiences without imposing pre-conceived theories or interpretations, in order to capture subjective perspectives and uncover the underlying structures of phenomena. The intent of utilising this method in this study is to gain a richer understanding of the burn survivor's 'lived experience' that may incorporate their liability in their injury.

Ethical Considerations

This work was considered as a continuation of a prior Service Evaluation project conducted within Buckinghamshire HealthCare NHS Trust therefore no additional ethical approvals were required. Adult patients (over 18 years of age), who had given their consent for their answers given in their Scar Clinic CARe Burns PROMs questionnaire to be used for Quality Improvement and Service Evaluation work were identified and contacted via telephone. They were informed their participation was voluntary; their identity would be anonymised at

the time of analysis with an assigned number and they could withdraw at any time without prejudice. They were informed their co-operation was appreciated but there would be no financial reimbursement for their time . They were made aware that should any of the process become too much for them they were able to access the support of the Burns Psychology team.

All transcripts were de-identified, whereby the names of places and people were removed and replaced with a generic phrase within parentheses. Significant details pertaining to the patient injury and demographics were withheld due to the small treatment population covered by the Stoke Mandeville Burns Unit.

Study setting and recruitment

Purposeful sampling was used to recruit participants to this study. Being the dominant sampling strategy in qualitative research made this an appropriate method to select the participants whose experiences of the chosen phenomenon would enable understanding of the research question. As the study utilised the phenomenology method, the intent was not to explore variables, rather the phenomenon of interest specific to the objective of the study, namely patient liability in their own injury. Participants were selected based on those that had sustained self-inflicted accidental injury, such as accelerant onto a bonfire/BBQ, as opposed to random selection of the entire patient cohort that had completed PROMs in Scar Clinic. Through review of the documented patient clinical journey, the liability for the injury can be identified – whether the injury was accidental, caused by the patient or caused by an external party. Understandably this is a controversial topic as placing blame for injury has been shown to hamper recovery after trauma in the context of road traffic accidents (201, 202), however there is no literature describing blame and recovery in the adult burn cohort, only in the parental proxy cohort when supporting their children.

Participants were required to be 18 years or older at the time of their burn injury and there was no time limit on how long ago their burn injury should have been sustained. There was no minimum TBSA burn and no specific anatomical area of involvement. Participants were required to be able to read and speak English in order to participate in the interviews. Specifically, any patients who had burns sustained as a result of deliberate self-harm or suicide were not invited to participate in the interviews, given potentially additional specific psychological needs (203).

In order to recruit patients, the researcher reviewed adult patients who had completed the CARe Burns Scale PROMs for Scar Clinic between May-November 2021 and had consented to their answers being used in future studies. Those patients' notes were reviewed through the Electronic Records System to determine the mechanism of injury. Identified patients were then contacted on their preferred telephone number by the researcher and the request for their involvement explained. If participants agreed to be involved their name and preferred contact number were recorded and a time decided that was mutually convenient for the researcher to call back and conduct the interview. The time between initial contact and conducting the interview was aimed at eliminating any threat of participation coercion by the researcher. All patients that met the inclusion criteria were contacted, not all decided to participate. Only telephone interviews were available as due to the Covid-19 pandemic, face-to-face interactions were avoided.

Data collection

The same sole researcher contacted all patients (n=8). Of the cohort, five agreed to participate. Semi-structured interviews were conducted over telephone on speaker setting allowing for digital recording. The words were transcribed verbatim onto TextIQ within

Qualtrics XM. All interviews and transcriptions were conducted by the same sole researcher. The same researcher also ensured anonymity of the data on the recording platforms. This style of interview was deemed most appropriate as it facilitates dialogue of participant views and has been demonstrated to be successful when discussing sensitive or traumatic experiences (196). Topics covered within the interview included: accounts of the injury, discussion of subsequent treatment, responsibility around the injury, negative or positive feelings surrounding injury liability, perspectives on their injury now and any future treatment hopes and expectations. The topics were devised with the Burns Psychology team and an interview topic guide utilised (Figure 9). Interviews were standardised whereby the same open-ended questions were asked to each individual in the same order to elicit spontaneous, non-biased reports, however opportunity for free discussion was given and any perspectives important to participants to arise naturally (196, 204). During the interview, the researcher prompted the participant to expand on particular points until data saturation was reached whereby no new themes were forthcoming**.** Ethical considerations were accounted for when conducting the interviews themselves, taking place in a personal and interpersonal context, signposting the content of the interview questions and giving patients the opportunity to terminate the interview at any time. The roles of the interviewer and interviewee were clearly explained, and the interviewee informed of the relevance of their collaboration. At the close of the interview patient demographics were clarified with the participant and cross referenced with the existing demographics captured by Qualtrics XM from their completion of their CARe Burns Scale PROMs.

Interview topic guide/transcript:

Introductions and nature of call reviewed – identities confirmed
Confirm time still convenient and participant agrees to proceed

Statement read: This is a semi structured interview that I will be conducting and recording for the study. I am the only team member on the call. All transcripts are held on a secure NHS server and all identifying features will be removed so your words are anonymous. Some of these questions are rather personal and you may find difficult to answer. If that is the case, please do not worry. We can have a general conversation at the end, so you have an opportunity to speak about anything troubling you. I am going to be asking you about how you feel around the day of your burn. If at any point you would like to stop, please do not hesitate to make this clear. If there are any aspects of the conversation you do not wish to be recorded, please let me know and we will stop. With the Burns Psychology team we have devised a simple script to prompt my questions but see this more as a free discussion. Your responses will be used to understand if there is additional support that can be provided after burn injuries to patients.

If patient agrees to proceed, interview commence:
Do you recall much from the day of your burn?
Can you talk me through the event and what treatments you received?
Do you think back to the day of your burn much in your everyday life now? - *Ask to elaborate*
Is there anything you feel you could have done differently? If so, what would this be?
What emotions do you have attached to your burn from the time of injury?
Have your feelings towards your injury changed over time?
Do you feel responsible for your own injury? If so, in what sense? Do you have any positive emotions around this?/ negative emotions?
Had your burn been caused by someone else; do you think you would feel differently about injury?
Have you noticed any positive changes in yourself since your burn that may be as a result of the injury?
Is there anything else around your burn and feelings associated with it that you would like to share?
Confirm injury mechanism
Thanks and close interview

Figure 9 – Interview topic guide and resulting transcript devised with the Burns Psychology team

Data Analysis Method

The sole researcher reviewed the anonymised transcripts and analysed them according to the seven steps method of Colaizzi (200) to unearth the 'lived experience' of the patient behind the interview text. All transcripts were cross checked by the researcher against the recorded interview to ensure no data was missing. Regarding the Colaizzi analysis, step one involved re-reading and immersing oneself within the transcript text to gain insight into the participant's 'lived experience'. Significant phrases and statements from participants were then extracted for step two – specifically those that pertained to the research phenomenon in question – liability, from the five transcripts. Meanings were then formulated by the researcher that related to the essence of participant statements for step three. For step four,

the formulated meanings were grouped into categories that were theme clusters. The clusters are grouped and coded as unique emergent themes from the transcripts. These themes are summarised for step five. The summaries were sent to the participants for step six so they could validate and confirm they reflect an accurate description of the lived experience discussed in the interview. Confirmation was received from 60% of participants and no new information was added. Despite multiple efforts to contact the remaining two, there was no success. Step seven of the Colaizzi method involves incorporating any new data derived from participant's validation, however nothing needed adding.

During the data collection, the technique of bracketing was employed to avoid infusing the researchers own beliefs and biases into the data set and enhance the trustworthiness of the study. In the phenomenology methodology bracketing is a key approach. In order to establish one's own predispositions, a bracketing interview was undertaken prior to the study as per Rolls and Relf (205) with the sole researcher and an uninvolved colleague, whereby the interview topic of liability in burn injury and positive growth was explored. Research annotations were completed during the process of the literature search and any preconceptions declared, again to reduce researcher bias and remove oneself from the research topic. These were also documented to demonstrate openness within the process and disclose decisions through the study for anyone to review. With no previous literature available specifically investigating the role of patient liability in burns trauma and emotional recovery preconceptions were limited.

Results and analysis

The sample population included three male and two female patients. Sample size could not be increased during the data collection period. From the sample, twenty-five adult patients had completed PROMs at the time of review in Scar Clinic. Eight of these patients met the inclusion criteria. This was due to nine patients having sustained their original burn injury before the age of 18 and eight patients' injuries being the result of deliberate self-harm. Of the total of eight that met the inclusion criteria, three declined to participate (Figure 10). The total interview time on average was 21 minutes (range 18 – 27 minutes).

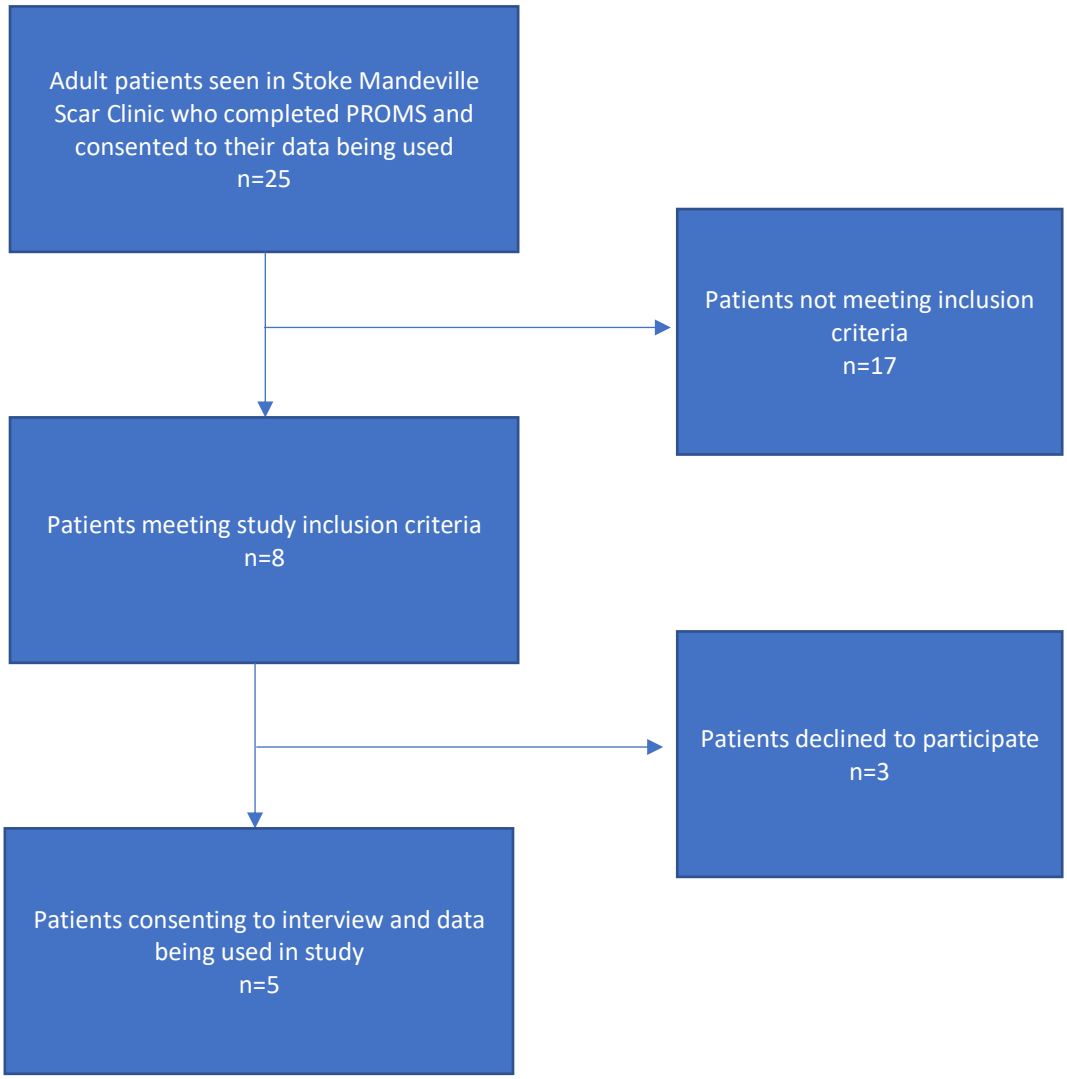


Figure 10 – Flow diagram documenting patient recruitment for interview

Demographics

The average age of participants was 43 years with a range of 21-64 years. On average the TBSA burned was 4%, the range being 1.5-7% TBSA. One patient had facial involvement from the burn. No patients were transferred to a Burns Centre to receive ICU care – all care was completed at the Burns Unit of Stoke Mandeville Hospital. The average length of stay in hospital was three days, range two-four days accounting for three of the patients. The remaining two patients were managed on an outpatient basis. The average time elapse since injury was 17 months (range 8months – 31months). At the time of their injury, one out of the five patients had follow-up with the burn psychology team.

Emergent theme and cluster themes

Despite the small number of patients, the emergent theme from the interview transcripts was clearly **Acceptance** (Figure 11). All participants demonstrated an awareness of their injury and shared insights into the challenges associated with moving forward after their burn. Specifically the interview directed participants to the concept of liability in relation to their burn and thus was identified as a cluster theme. A further two cluster themes were identified as relief and humour. To evidence these themes, specific excerpts have been extracted from the transcripts that best represent the cluster themes, however equivalent phrases were apparent in other transcripts.



Figure 11 – Diagram of emergent theme of acceptance with related cluster themes following patient interviews

Relief

Observed throughout the transcripts there was the sense of relief experienced by the participants. The notion of confronting the potential gravity of injury that could have ensued, patients reported feeling they had a fortuitous outcome. Two of the participants were injured outdoors when putting accelerant onto a BBQ in one case and a leaf pile in the other. During this time, their family were present, including small children in one case. This participant described the relief that it was they who sustained the injury as opposed to their offspring: *"…I do go over the scene and I just think 'what if it had been him?'…I don't think I'd be able to forgive myself…You know I'm sometimes almost pleased it was me, I can't even imagine how it would be if he got burned and it was my fault…and he'd have to go through all that hospital stuff"* (Patient E). Patient D had facial burns as part of their presentation and required skin grafting to the upper limb. They described the relief relating to the healing capacity of their face: *"…I'm just so pleased with how well my face has healed…imagine if this* (referring to the graft) *was on my face or something…."* (Patient D).

During the interview, one participant compared their injuries to a colleague who had the same mechanism of burn but required surgical intervention through delay in presentation: "*I think if I'd have left it longer then I would have needed an operation (*referring to quickly applying first aid)*…I have a mate on the site that had the exact same thing happen and he had to have an operation and one of those skin grafts…I guess I'm pretty lucky in a way you know? Yeah, I was off for a bit but it's all sorted now"* (Patient C). This participant reported finding some level of comfort in comparing their burn outcome to that of a colleague and reporting the relief he feels that the injury had been managed appropriately. This participant expressed a level of gratitude related to the knowledge he gained from experiencing another member of their team go through the same injury and felt confident they could recover, as both have returned to work.

Humour

It appeared that humour played an important role in the recovery of the interviewed participants, with all making light of the experience in hindsight. They used this as a means to accept their injury and cope with the long-term effects. One participant who spent time as an inpatient on the Burns Unit reported how the team being in such high spirits helped them come to terms with the injury. They were wearing a hand-bag as part of their treatment and they recall exchanging jovial remarks with the nursing staff as this being a means to give up smoking. Another patient commented on the irony of their injury mechanism being flame with their treatment dressing being flammable. This is a phenomenon of humour to cope with tragedy that has been identified in other studies relating to burn trauma (144).

Liability

Observed throughout all participant transcripts was the notion of the patients being liable for their injury. Every patient discussed the role of taking responsibility for their burn injury and this assisting them with coming to terms with the trauma: *"this was all totally my fault…I knew it would happen, I didn't have my knee pads…thought I could just get the job done quickly…"* (Patient E).

Patient B explains, recounting adding lighter fluid to a bonfire: *" It seemed like such a good idea at the time though…things weren't happening, thought I'd help it along…not the best idea and it was completely my fault."*

Discussion

This was a phenomenological study aiming to explore whether liability played a factor in positive growth after burn injury. The use of the descriptive phenomenological framework allowed for a discussion with patients through semi-structured interviews in order to explore specific characteristics that may account for a more positive personal outcome. The main emergent theme was that of acceptance, with the three sub-themes of relief, humour and liability. Work completed by Kornhaber et al (144) also used the phenomenology methodology. Their findings pertained to burns survivors of major trauma in Australia (>20% TBSA). Although their emergent theme was that of acknowledgement with sub-categories focused on reasoning, self-awareness, the challenges of acceptance, and humour, there are certainly some similarities drawn from our cohort. The mirroring of the cluster theme of humour noted in this study, and in other studies, focused on patient growth post trauma (206-209). Humour has been established as an adaptive coping mechanism for overwhelming experiences and forms a part of everyday living. It has been accepted by studies as a means of individuals interpreting their own health status, however more work in this realm is required to understand the extent of the relationship between humour and health (210-214) Although within a small cohort, this study does in fact identify the importance of humour when moving forward from burns trauma and may influence positive growth after injury.

The data provided by the participants during their CARe Burns Scale Questionnaire was reviewed with particular scrutiny relating to the positive growth subscale of the PROM whereby patients are asked if the burn injury has changed them as a person in a positive way. It is accepted that no correlation between the positive growth domain in the PROM can be attributed to the themes identified through the qualitative data collection. This is due to interviews being semi-structured with a topic guide, which did not explore wider patient

factors such as social networks and family support that may have contributed to positive growth post burn injury. The relevance of reviewing the participant's positive growth domain was to identify whether any had demonstrated a high value in this area. All participants did demonstrate a high value in the positive growth domain, and while acceptance of their injury with the assistance of humour and feelings of relief and liability may not be the causative factor in this growth, it appears to be a relevant area of interest that warrants further study.

The emergent theme from this study was acceptance. Patients discussed the challenges they faced with accepting the reality of the injury event and modifying their future behaviour. It is well established that an altered physical appearance after injury can become problematic during burns rehabilitation (215) and therefore accepting physical appearance is key to moving forward (216-218). This study did raise acceptance as a theme, however it relied more on an emotional acceptance rather than the physical manifestations of the burn such as scarring. Should this work be repeated, insight into the patient perception of the physicality of their injury would be a useful topic to explore, particularly in the context of positive growth after injury, especially as Fauerbach et al have reported that dissatisfaction with body image can hamper psychological and physical recovery post burn (218). Results of this study concur with that of Kornhaber et al and Moi and Giengedal in so far as two of the participants felt they needed to accept what is unchangeable in order to recover and be open to modifying their activities to avoid a repeat of the injury (144, 219).

Of the participants, only one had facial involvement with their burn. The patient reported being pleased with the outcome and having no residual scar. They explained that should the scar to the forearm match that of the face they felt they would have had greater difficulty accepting their injury and returning to their pre-morbid state of socialising and family interactions. This is in line with studies concluding facial scarring can result in poor social

adjustment **(**221**).** The participant mentioned that they avoided looking in the mirror until their partner had confirmed their burns had healed, as they felt unable to confront their injury so acutely, a phenomenon noted by Egan et al and Redstone at al (215, 220).

A novel theme that arose from this small cohort was that of relief. Patients commented they were relieved the injury affected them rather than their children or family members. This protective characteristic may reflect a more optimistic emotional state and may also play a role in positive growth post burn trauma.

It is well established there are both physical and psychological challenges associated with adjustment post burns and therefore it is unsurprising that those that sustain severe burns can experience difficulty in adapting to life after trauma. Having an understanding of the phenomenology that can influence PROMs can assist clinicians in supporting their patients through the rehabilitation process. Although this study was a small sample size, it did reveal a potential new route for further investigation – that being the patient responsibility for their own injury – and the acceptance of that liability potentially having a beneficial impact on positive growth. To take the notion of liability or responsibility having an impact on PROMs and, in particular, the positive growth domain in burns care, further work needs to be undertaken, firstly with a larger number of participants but also in investigating those specifically with a more negative documented outcome from their burn experience.

Limitations

Whilst the study sample of n=5 is small, the results do contribute to the growing body of knowledge relating to positive growth post burn injury. However the applicability and transferability of results may be limited due to the nature of the study design. Qualitative research is deemed less objective and risks the introduction of the researcher's subjective

opinion. Although every effort was made to avoid this through bracketing, since there was only a single researcher, there was no opportunity to discuss preconceptions and attempt their removal. The use of a bracketing interview conducted by an uninvolved party was a means by which to reduce researcher bias. In order to maintain trustworthiness in the process of data collection and analysis, the researcher had a protracted period of time with the transcripts to fully immerse in the data, demonstrated verification of findings with extracts of participant narrative and kept documentation of research annotations. Following Colazzi's steps for data analysis involved returning transcripts to participants. Although participants had no additional information to add, this does not confirm the strength of the study, in fact in may relate to the semi-structure interview transcript being too limited to delve deep enough into the patient 'lived experience' for them to feel they had anything of relevance to add.

The study was conducted within the UK with participants who had undergone treatment in an NHS facility. This model of care is not reflected globally, therefore patient experiences will differ across care systems, making the transferability of results somewhat limited.

As the study utilised purposeful sampling, only those that wished to partake were interviewed. This would introduce the factor that those more extroverted and accepting of their injuries were more forthcoming, therefore this may not be a true sample of the 'lived experience' post burn. Furthermore, there was no limitation on the time since injury and the interview. The longest time between injury and interview was 31 months, risking recall bias in the participants as there is potential for recollection to become altered with time (222).

The decision was made to undertake the phenomenology methodology of qualitative data analysis in order to mirror existing research around the topic of the 'lived experience' in burns. Although alternative methods of analysis for qualitive data exists these were deemed inappropriate. Coding reliability thematic analysis would necessitate the work of multiple

coders and is a means designed specifically for research teams. Although this reduces the bias within the study, it was a resource not available in this case. Codebook thematic analysis was also not instituted as the deductive approach utilising predetermined thematic codes for this work does not presently exist. Finally, an alternative to the interpretive phenomenological analysis could have been reflexive thematic analysis. Since the group of interest was small, the data collection method was interviews only and the work was based on 'lived experience' rather than emergent themes from large datasets (seen in reflexive thematic analysis), the phenomenological method was more appropriate.

Due to the Covid-19 pandemic, interviews had to be conducted over the telephone. Conducting interviews over the telephone comes with its own limitations. Had it been possible, interviews would have been conducted face to face to allow for both verbal and non-verbal communication. Without the ability to view patient gestures, facial expressions and body language, it was difficult to assess how well the interview was going or whether the interaction needed to be managed alternatively. No patient seemed dissatisfied with the interview and no patient had any additional comments to make at the interview close, however it is a concern to be aware of if these types of interviews were to be repeated – face to face would give a richer experience.

Conclusion

This is a descriptive study utilising the phenomenology methodology to explore whether patient's own liability regarding their burn injury had any influence on their positive growth after the trauma. Although through purposeful sampling and semi-structured interview with topic guide elicited emergent themes of Acceptance, it was cluster themes of humour, relief and liability that were noted. It is therefore unclear whether liability itself plays a key role in positive growth post burn injury. The findings do highlight the

challenges that those who have suffered a burn injury face and consequentially provides insight into the perspectives of those managed within the UK NHS system who have sustained burns. The findings add to the growing body of evidence relating to the support burn survivors require in the rehabilitation phase of their injury.

Patients within the study had burn areas ranging from 1.5-7% and although at the time of their injury, only one patient engaged with the burn psychology team, their readiness to interview for the study and discuss their injury suggests a greater number of patients may benefit from interaction with the psychology team, although this is a challenging direction given limited resources.

Closing Statement

This work set out to explore the PROMs and ClinROs utilised in burns care. In doing so, appropriate measures were identified that would be feasible for the application in the MDT Scar Clinic of a Regional Burns Unit.

During a six-month data collection period, all patients had the selected ClinROs applied and were invited to complete PROMs. Of the patients that had both scales completed, there was noted to be a varying degree of correlation between the measures. However, there was also noted to be a certain level of discordance, whereby the scales did not appear to capture all information pertaining to the patient burn that may be affecting the outcome.

The clinical journey of each patient was explored, and preliminary results identify correlations with the %TBSA affected, however further work is required to understand additional features of the burn presentation that may act as predictors of the chosen outcome measures.

Finally, the novel notion of patient liability in relation to their injury was explored, with early results suggesting that acceptance of liability may have a role to play in positive growth after a burn injury.

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