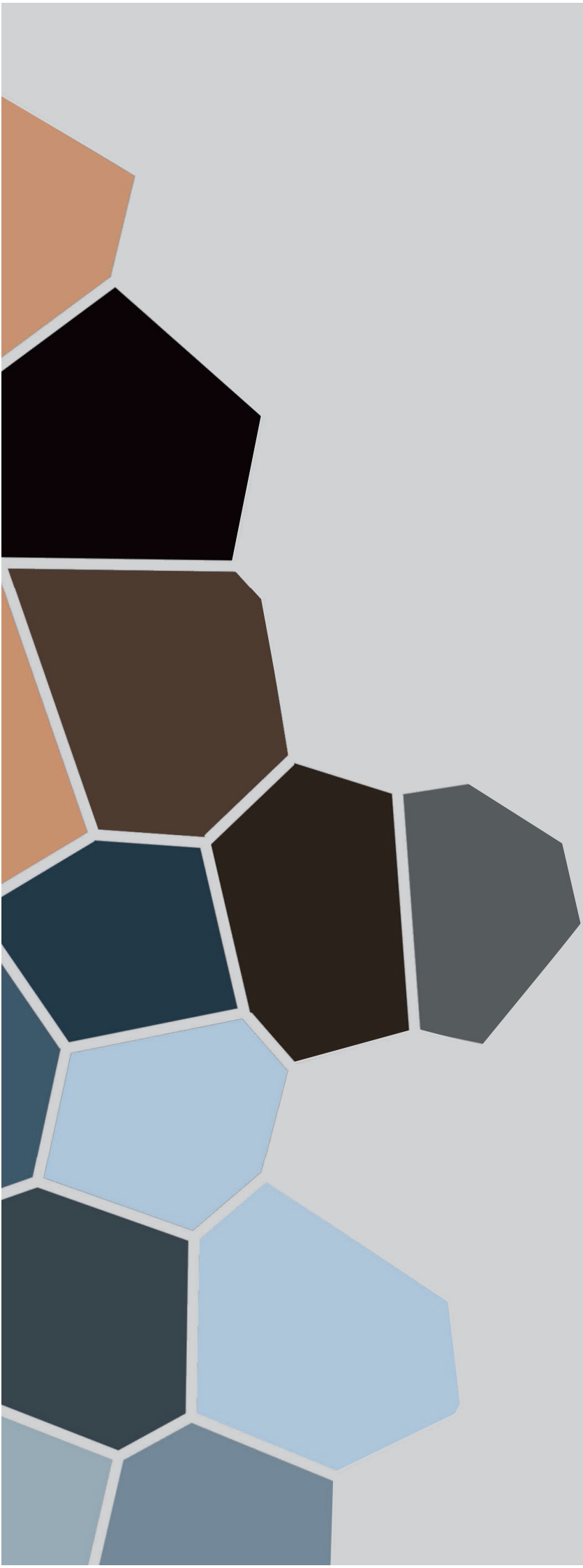
Scope

PART I



CHAPTER 1

Introduction and outline of this thesis

Burns are an important health problem. Worldwide it is estimated that each year 195.000 people die as a result of burns [1] and almost 11 million people require burn-related medical attention [2]. Medical attention in the acute phase of a burn can vary between a single visit to a general practitioner (GP) and a lengthy admission to a specialised burn centre. Especially people admitted to a burn centre may require additional medical attention after discharge since those people are on average more severely burned. Medical attention after discharge could involve outpatient wound management, scar treatment and psychosocial aftercare. Whereas outpatient wound management stops after wound closure, scar treatment and psychosocial aftercare could be a lifelong endeavour. Treatment options vary and depend on the severity of both physical and emotional scarring. For instance, scar treatment could involve pressure garments, splinting, silicones, laser therapy, massage, corticosteroids, and reconstructive surgery [3-9], whereas psychosocial aftercare varies from a conversation with an aftercare nurse to participation in burn camps [10] and individual therapy. All these treatments are incorporated in the multidisciplinary approach of specialised burn care in order to strive for the best possible outcome for a burn survivor.

It is of interest to study the long-term outcome of a facial burn injury. Not only because the face is important for cosmetic reasons, it also represents our identity, is our most expressive means of communication and harbours basic abilities such as hearing, smelling, seeing and breathing [11,12]. All these facial features can be affected by a burn injury or its sequelae. For instance, facial scarring can cause an ectropion or a microstoma, preventing the closing of the eyes or the opening of the mouth, respectively. Both functional and aesthetical problems could cause an additional problem with social interaction as an attractive appearance is, from a societal perspective, regarded as important. A recent study showed that normal facial appearance was rated as very important in order to be a functioning member of American society [13]. This was in line with another study in which adult volunteers (n = 210) evaluated photographs of people with facial deformities and digitally altered photographs of the same people without their facial deformity. Results of that study showed that people with facial deformities were evaluated significantly less honest, less employable, less trustworthy, less optimistic, less effective, less capable, less intelligent, less popular and less attractive compared to the same people without facial deformities [14]. Both studies illustrate that living with a facial disfigurement in a society that highly values appearance can have significant impact, and this may additionally affect someone's psychosocial well-being.

A burn survivor's psychosocial well-being is likely to be subject to change rather than to remain in a steady state. A grounded theory based model developed in cancer patients with facial disfigurements [15] describes three different stages that might be helpful to frame and understand the burn survivors psychosocial transition. In addition, the burn survivors psychosocial well-being is strikingly illustrated by the story of Katie Piper [16]. She described

her experiences of severe facial burns, from the moment she was attacked with acid to the aftermath of the burn injury, that can be matched to the different stages in the model.

The first stage is called 'becoming disfigured' and covers the event, in this case the burn injury, and the time spent in the protected area of a hospital. Especially the painful and distressing experience of a burn injury might have significant impact on a burn survivor psychosocial well-being.

> *From the top of my head all the way down to my feet, every inch of me was in agony. And my face… I could feel it burning, burning so hot I thought it was going to burst into flames. I lurched away a few metres, oblivious to everything around me, doubled over in pain. With every second, the agony clawed its way deeper and deeper into my skin. I heard a horrible screaming sound, like an animal being slaughtered. What was making that noise? Then I realised it was coming from me.*
> (Katie Piper, after being attacked with acid in: Beautiful, p. 74 [16])

During the time spent in the hospital, the burn survivor is surrounded by other burn survivors, possibly with similar disfigurements, and medical staff that are used to the appearance of facial burns. Obviously this period could be very distressing, however the burn survivor finds oneself in a controlled environment where it is safe to get used to one's new appearance.

> *It was worse than I ever could have imagined. My face was red raw. I was a piece of rotting meat. I had known my eyelids were missing and that my head was shaved, but where was my tanned skin? Where was my neat nose? Why did my lips look like they'd been pulled inside-out? And my eyes, oh my eyes! The left was milky and blind and the other was empty, like it belonged to a corpse. My old face was gone: there was not the smallest sign of it in the reflection that stared back at me. This was my new face […]. This was me.*
> (Katie Piper, seeing the reflection of her face in a mirror for the first time after an acid attack in: Beautiful, p.107-8 [16])

The second stage is called 'being a disfigured person' and starts after discharge when the burn survivor leaves the protected area of a hospital and returns to everyday life. In this 'new' life with a facial disfigurement the burn survivor is exposed to reactions of others, both relatives and strangers, when they notice the disfigurement. These reactions could include silencing, staring, avoiding or even name-calling, but all cause the burn survivor to remember one's facial disfigurement.

> *As soon as I got into his car, I could tell it was awkward. He didn't screw his face up or gasp, but his feelings were as plain as day. It was there in his uncomfortable 'Hello', in his subdued demeanour, in the look in his eyes. I wanted to burst into tears.*
> (Katie Piper, picked up for a second date in: Beautiful, p. 296 [16])

In order to reduce these events, a burn survivor could develop avoidance behaviour as a coping strategy. Although this strategy could reduce painful situations in the short term, it does not allow the burn survivor to progress to the next stage, that is 'becoming a person with a disfigurement'. According to the model, the transition into this stage occurs through breaking the silence, either by others or by the patient [15]. This stage is characterised by the burn survivor's acceptation of the facial disfigurement, however, this final stage is an unstable stage. For instance, insecure burn survivors or those that highly valued appearance before the burn injury might be vulnerable to regression to the second stage as a result of an unsuspected remark by others or the recollection of their life before the burn injury.

> *I wasn't naïve enough to think it would be plain sailing from here on in. I would be back in hospital for more treatment, more operations, more consultations, more complications, but that was okay. And I would still have bad days, when I wasn't happy with how I looked – but every girl had those, right?*
> (Katie Piper, showing her new flat to her parents that symbolises a new chapter in her life in: Beautiful, p.305 [16])

Although the above model is developed in cancer patients following facial operation, a similar trajectory might exist in burn survivors with facial burns. In addition, only few publications specifically focus on facial burns. In order to reduce that gap, this thesis focuses on facial burns and uses the above model to frame the epidemiology, treatment and psychosocial impact of facial burns.

Epidemiology

First, it is essential to acquire a general overview of the magnitude of the problem, that is, who is 'becoming disfigured'. Literature on the epidemiology of burns in the Netherlands is limited to burns in general [17,18] or focuses on a specific population, for instance children admitted to Dutch burn centres [19]. Because previous studies did not focus on facial burns, we undertook an extensive epidemiological study on facial burns **(Chapter 2)**, investigating not only facial burns in burn centre admissions but also in general hospitals and emergency departments (ED). Besides an overview of facial burns in the Netherlands, we identified predictors of facial burns, predictors of facial surgery in the acute phase aimed at wound closure and predictors of facial reconstruction in those patients admitted to a Dutch burn centre. Furthermore, we provided a brief overview of conservative treatments for facial burns applied in Dutch burn centres.

Evidence Based Treatment

The **second part** of this thesis elaborates on treatment for facial burns, which is important for the physical outcome of the burn and subsequently the outcome of 'becoming disfigured'. Treatment of burns can roughly be divided in topical therapy and surgical therapy. With regard to topical therapy, there are numerous creams, ointments, dressings or other alternatives that could be applied to the burn wound. New products with potentially better healing properties are brought to the market every year, increasing the options for burn specialists. The downside of the numerous options is that it is hard for the burn care specialist to determine the best treatment option. This problem does not only arise in burn care but exists in all medical disciplines. In order to practise evidence based medicine, specialists need to invest much of their time to stay up-to-date with the literature and new developments. Instead of searching for high quality comparative studies and reading all relevant articles separately, they could save time by reading reviews that summarise the evidence. The gold standard of reviews is set by the Cochrane Collaboration, an international not-for-profit organisation. The goal of the Cochrane Collaboration is to produce high quality relevant, up-to-date systematic reviews to inform health decision-making and to make this evidence accessible and useful to everybody, everywhere in the world [20]. In order to provide burn specialists an overview of the best evidence on topical treatment for facial burns we conducted a Cochrane systematic review on this topic **(Chapter 3)**.

Besides topical treatment, there is also debate about surgical treatment, especially regarding the optimal timing of surgery. With regard to facial burns there is a tendency to a more conservative approach, that is waiting until it becomes evident what heals and what does not. In other body parts however, there is more disagreement between professionals that advocate early excision and those that advocate conservative treatment. In **Chapter 4** we focus on this topic in another Cochrane systematic review. Because the discussion about optimal timing for surgical intervention is not limited to facial burns but applies to all body locations, we did not restrict our search to facial burns alone. Instead we included all randomised controlled trials on early excision and grafting for burns and planned to perform a subgroup analysis for facial burns.

Psychosocial Impact

The **third part** of this thesis focuses on psychosocial aspects of facial burns that might be related to the transition of 'being a disfigured person' to 'being a person with a disfigurement'. Because facial burns and facial scars are visible to others, it is conceivable that facial burns elicit psychosocial difficulties, for instance with regard to self-esteem or depressive symptoms. Whether these difficulties are related to the severity of the burn is still under debate, and in addition, which measure of severity should we use? Although percentage Total Body Surface Area (TBSA) burned is a measure of burn severity, it is not necessarily an adequate measure

in relation to long-term outcomes, like psychosocial consequences. A more suitable measure would possibly be the severity of scarring. The severity of scars can be objectively quantified with measurement tools that measure one scar characteristic, usually the colour, thickness, relief, pliability or surface area of the scar [21]. Examples of those instruments are the cutometer that measures skin elasticity, the dermospectrometer that measures colour or the Primos that measures surface roughness. In contrast to objective scar assessment tools, subjective scar assessment tools are generally developed to measure more than one scar characteristic, usually a combination of colour, texture, thickness, pliability, surface area, pain or itch of the scar [22]. Especially the subjective Patient and Observer Scar Assessment Scale (POSAS) [23] (www.posas.org) is widely used and represents the patient's and observer's perceived scar severity. The added value of the POSAS is that the patient's experience is incorporated in the assessment of the scar. Concurrently, this raises the question whether the patient's scar assessment measures the physical characteristics of the scar or the psychosocial wellbeing of the patient or both. A comparison between the patient and observers scar assessment on similar items of the POSAS could help resolving this question. However, the level of agreement between patient and observer scar assessments is unknown. This is investigated in **Chapter 5** and additionally we investigated whether scar assessment is related to the patient' self-esteem.

A well-known theory in sociology is the Thomas theorem that states that "If men define situations as real, they are real in their consequences" [24]. In line with that theory, it can be hypothesised that the patient's self-reported facial scar severity could act as a possible influencing factor on the patients psychosocial wellbeing. Two psychosocial aspects that can be used as a measure of psychosocial wellbeing are self-esteem and depressive symptoms, both commonly reported in the aftermath of a burn injury [25] and related to each other [26,27]. The influence of the patient's self-reported facial scar severity on self-esteem and depressive symptoms, as well as whether low self-esteem precedes depression or the other way around, is still subject of debate. Nowadays, advanced analytical methods are available that investigate such relations in one model, taking into account all relations. The relations between patient's self-reported facial scar severity, self-esteem and depressive symptoms are investigated with such a model in **Chapter 6**.

Research Aims

Based on the scarcity of literature that focuses on facial burns and the potential impact of facial scarring, this thesis aimed to provide an extensive overview of the trajectory of facial burns, from incidences and risk factors to treatment modalities and psychosocial consequences after a facial burn.

Specific aims of this thesis were to:

- Assess the epidemiology of facial burns in the Netherlands and identify risk factors for facial burns, facial surgery and facial reconstruction.
- Provide the state of the art evidence in topical and surgical treatment for facial burns.
- Investigate patient reported facial scar severity and the relationships with self-esteem and depressive symptoms in people with facial burns.

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