Use of Healthcare, Perceived Health and Patient Satisfaction in Patients with Burns

BJÖRN WIKEHULT
Dissertation presented at Uppsala University to be publicly examined in Enghoffsalen, ing. 50, Akademiska sjukhuset, Uppsala, Friday, October 3, 2008 at 09:15 for the degree of Doctor of Philosophy (Faculty of Medicine). The examination will be conducted in Swedish.

Abstract

A severe burn is a trauma fraught with stress and pain and may change the entire course of life. This thesis focuses on care utilisation, care experiences and patient satisfaction after a severe burn.

The patients studied were treated at the Burn Unit at Uppsala University Hospital between 1980 and 2006. Burn-related health was examined using the Burn Specific Health Scale-Brief (BSHS-B), personality traits with the Swedish universities Scales of Personality (SSP), psychological symptoms using the Hospital Anxiety and Depression scale (HADS), symptoms of posttraumatic stress with the Impact of Event Scale-Revised (IES-R) and satisfaction with care using the Patient Satisfaction-Results and Quality (PS-RESKVA) questionnaire.

Those utilising care years after injury reported poorer functioning on three of the BSHS-B subscales. Personality traits had a greater impact on care utilisation than injury severity.

Social desirability was lower among care utilisers and was associated with burn-related health aspects.

The participants reported a low level of negative care experiences, the most common of which was Powerlessness.

Most patients were satisfied with care, more with quality of contact with the nursing staff, and less with treatment information. Multiple regressions showed that the BSHS-B Interpersonal relationships subscale was an independent variable related to all measured aspects of patient satisfaction. The highest adjusted R² was 0.25.

In a prospective assessment with multiple regression analyses, Age and Education, the personality traits of Stress susceptibility, Trait irritability, Detachment and Social desirability, in addition to the post-traumatic stress symptoms Intrusion and Hyperarousal, were predictors of satisfaction with care. The highest adjusted R² was 0.19.

The thesis has pointed out that interpersonal factors are related to care utilisation as well as satisfaction with care. However, satisfaction with care was only moderately associated with health and individual characteristics, which may imply that the care itself is of major importance.

Keywords: Burns, health status, care utilisation, rehabilitation, personality traits, care experiences, patient satisfaction

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To my family
List of publications

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:


V  Wikehult B, Ekselius L, Gerdin B, Willebrand M. Prediction of patient satisfaction with care one year after burns. Burns. Accepted for publication.

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### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>ANOVA</td>
<td>Analysis of Variance</td>
</tr>
<tr>
<td>BSHS</td>
<td>Burn Specific Health Scale</td>
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<tr>
<td>BSHS-B</td>
<td>Burn Specific Health Scale – Brief</td>
</tr>
<tr>
<td>DSM-IV</td>
<td>Diagnostic and Statistical Manual of Mental Disorders 4th version</td>
</tr>
<tr>
<td>EQ-5D</td>
<td>EuroQol Five Dimensions</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
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<tr>
<td>HADS</td>
<td>Hospital Anxiety and Depression Scale</td>
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<tr>
<td>HRQoL</td>
<td>Health-Related Quality of Life</td>
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<tr>
<td>ICU</td>
<td>Intensive Care Unit</td>
</tr>
<tr>
<td>IES</td>
<td>Impact of Event Scale</td>
</tr>
<tr>
<td>IES-R</td>
<td>Impact of Event Scale – Revised</td>
</tr>
<tr>
<td>KSP</td>
<td>Karolinska Scales of Personality</td>
</tr>
<tr>
<td>LOS</td>
<td>Length of Stay</td>
</tr>
<tr>
<td>M-C SDS</td>
<td>Marlowe-Crowne Social Desirability Scale</td>
</tr>
<tr>
<td>NEO PI</td>
<td>NEO Personality Inventory</td>
</tr>
<tr>
<td>PS-RESKVA</td>
<td>Patient Satisfaction, Results and Quality</td>
</tr>
<tr>
<td>QCN</td>
<td>Quality of contact with the nursing staff</td>
</tr>
<tr>
<td>QCM</td>
<td>Quality of contact with the medical staff</td>
</tr>
<tr>
<td>INF</td>
<td>Adequate treatment information</td>
</tr>
<tr>
<td>GS</td>
<td>Global satisfaction with treatment</td>
</tr>
<tr>
<td>PTSD</td>
<td>Posttraumatic Stress Disorder</td>
</tr>
<tr>
<td>QoL</td>
<td>Quality of Life</td>
</tr>
<tr>
<td>SCID-I</td>
<td>Structured Clinical Interview for DSM-IV Axis I Disorders</td>
</tr>
<tr>
<td>SD</td>
<td>Standard Deviation</td>
</tr>
<tr>
<td>SF-36</td>
<td>Short Form – 36 Health Survey</td>
</tr>
<tr>
<td>SSP</td>
<td>Swedish universities Scales of Personality</td>
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<tr>
<td>TBSA</td>
<td>Total Body Surface Area</td>
</tr>
<tr>
<td>TBSA-FT</td>
<td>Total Body Surface Area of the Full Thickness Burn</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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Introduction

The burn injury

The term “burn injury” is used to include thermal, electrical and chemical injuries. The most common causes are exposure to hot fluid, fire, or contact with hot objects. Most burns involve a partial or total, reversible or non-reversible destruction of the skin, and the severity of the injury depends on its extent, depth and localisation. The extent is defined as the percentage of the Total Body Surface Area (TBSA) that is damaged. The depth is characterised by the extent to which the layers of the skin are damaged and commonly described as epidermal, dermal or full thickness. While a superficial burn heals spontaneously, a deeper burn damages the stem cell pool required for healing. Deeper burns, therefore, do not heal spontaneously.

A major burn is life threatening. However, most persons exposed to a burn injury survive and recover after a shorter or longer period. The recovery is sometimes quite cumbersome and both the injury and the time thereafter will often remain in the memory as very stressful. For some patients, life will never be the same as before the injury. In addition to the psychological burden caused by the memories of the time after the injury, there is more or less permanent skin damage, sometimes debilitating.

Epidemiology

In a global perspective, burns are a major cause of premature mortality and years lived with disability [77]. The incidence varies greatly and is highest in developing countries, where open fire or flammable fuel is used for cooking, lighting and heating. The main cause of burns among children admitted to a burn centre is scalds by hot liquid, while flame is the most common among adults [83]. The usual setting for burn injuries is the home [2].

In Sweden, the incidence of burns admitted to hospital was 11/100 000 inhabitants in 2006 [3]. About two thirds were male. Other risk groups are children, the elderly and disabled persons [83].
Burn care

Burn care aims to ensure survival with minimal loss of function and subsequent adaptation. It commences with a period of highly specialised intensive care characterised by measures to combat the initial response to the burn insult and close monitoring of all vital functions as well as support of basic bodily functions such as nutrition and elimination. At this time the main problem is fluid loss and profound local and general oedema as a consequence of immediate changes in the microcirculation of the skin. An early treatment strategy is therefore fluid resuscitation, which further increases the general oedema [9] and together with inhalation injury may cause ventilation problems. Shortly thereafter, many patients will require ventilatory support, during which time they are intubated or have a tracheostomy [53]. Pain is often severe in the acute phase.

As the dead burned tissue serves as a focus for infection, which is the main cause of mortality, an explicit strategy in burn care is “to turn the burn wound into a normal wound”, and to do so as soon as possible. This involves surgical interventions comprising excision of necrotic tissue and skin grafting in wounds that are so deep that they are not expected to heal by themselves.

Rehabilitation measures start at day one in the form of maintenance of mobility and positioning to minimise complications and proceed in a structured fashion until the patient is fully conscious and can actively contribute to measures aimed at regaining the strength and functions lost due to injury and during care.

Stress and pain during care

Pain is a major problem in burn care. In general, it is related to open wounds, thus measures to increase the speed of healing have beneficial effects. Pain is highly variable between patients as well as between different days of care [19].

Pain can be categorised into non-procedural (background) and procedural pain. Non-procedural pain is the pain perceived when the patient is lying flat in bed and avoids any tasks that may affect his/her wounds. Procedural pain is related to all procedures which involve wound care or manipulations with the wound, such as pressure and stretching. In addition to changes of dressing, nursing care procedures and mobilisation are also perceived as painful and distressing [62].

Many patients experience more or less intense psychological reactions during burn care. The most common are anxiety, depression, psychosis/delirium and behavioural problems. The reasons are manifold. Psychiatric history including substance abuse, pain, medication, sleep disturbances
and the overwhelming neuro-endocrine activation after trauma all contribute [79, 84, 104]. Psychological reactions during the period in the Intensive Care Unit (ICU) may also be related to the length of time on the ventilator, during which the patient may have only been superficially sedated and given intra-venous opioids [92]. Patients often report negative emotions during the hospital stay, e.g. helplessness, or feeling like a victim of fate [7]. Patients in general ICUs, as well as in acute and surgical care, have reported a sense of vulnerability due to insecurity and fear concerning their medical condition, are afraid of being a nuisance to the staff [96] and describe feeling safe or frightened, alone or monitored, powerless, hopeful or hopeless, or experiencing acceptance or apprehension [41, 47, 89].

In general, there is an interrelation between pain and anxiety. First, anxiety may be aggravated by pain and, second, pain may be aggravated by anxiety. Since the painful procedures are repeated on a daily basis for a long period, many patients will experience anticipatory anxiety related to the expected pain. In turn, the pain will be perceived as worse due to the anticipation.

Nursing care

Nursing a patient with a burn injury is not basically different from caring for a patient with any other medical condition. It implies a high degree of understanding of the condition in question and of the measures required to combat the physiological changes that follow. It also means adequate knowledge of basic intensive care and of handling the burn wound. Furthermore, it presupposes a perspective on the psychological response to the burn trauma as well as knowledge of how to support the individual patient during the sometimes long care period. The round-the-clock presence of a member of the nursing staff constitutes psychological support at this time.

Outcome following burns

Health

Health is best defined as “… a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” [107]. Health-Related Quality of Life (HRQoL) is a subjective measure of physical, mental and social wellbeing that also comprises the individual’s perception of how an injury or illness interferes with his/her ability to live a fulfilling life [40]. Assessment of HRQoL is usually conducted using generic multidimensional self-report instruments such as the Short-Form 36 Health Survey (SF-36) or the EuroQol Five Dimensions (EQ-5D). Burn trauma may lead to long-term
problems in all the domains described above, i.e. physical, mental and social
[74].

The first year after a burn is described as the most challenging phase of
rehabilitation. During this year, most patients with moderate burns more or
less recover. However, in general, patients with burns experience lower qual-
ity of life and higher levels of emotional distress than the normal population
[80]. In a longer perspective, the findings differ somewhat between studies.
In a study conducted on average 4 years after a burn event, the SF-36 re-
vealed that patients had significantly lower HRQoL, but their overall quality
of life was similar to that of the general population [75]. In a matched-
control study 2-10 years after the injury, patients with burns had similar
HRQoL according to the SF-36, but significantly more psychological prob-
lems compared to a non-burned control group [5].

Burn-specific health

Patients with burns present specific health issues that are not covered by the
generic instruments. Although many recover during the first year after a
burn, a subgroup of patients report burn-related physical and psychosocial
problems several years after the injury [59, 67, 68, 113]. In an early inter-
view study, the most frequent and serious problems were skin- and appear-
ance-related [15]. Problems with thermoregulation and hypertrophic scar-
ring, which may lead to skin contractures with joint deformities and a de-
creased range of motion, frequently occur. Other common skin-related prob-
lems are pruritus and pain. Changes in appearance due to skin abnormalities
or amputation may also lead to body image dissatisfaction and affect both
subjective self-image and social comfort [33].

Assessment of burn-specific health status requires an injury-specific in-
strument that is appropriate at different time points. One such injury-specific
and multidimensional instrument is the Burn Specific Health Scale (BSHS)
[12], which covers physical, mental and social domains of health and spe-
cific problems caused by burns, such as heat sensitivity and body image. The
BSHS has been revised several times [14, 76] and a psychometrically evalu-
ated brief version, the Burn Specific Health Scale-Brief (BSHS-B), has been
developed by the Uppsala Burn Research Programme [58, 111].

Psychological outcome

The most common psychological problems after burns are symptoms of de-
pression and anxiety. Depression is a mood disorder characterised by de-
pressed mood and/or loss of interest, changes in psychomotor function, sleep
pattern and weight, lowered energy, inability to concentrate, poor self-
esteem and sometimes suicidal thoughts or acts. Posttraumatic stress disor-
der (PTSD) is an anxiety disorder that can occur after exposure to traumatic
events involving a moment of extreme fear or helplessness. It is manifested
as symptoms of 1) intrusion, which involves an unwanted and distressing re-
experiencing of the event in thoughts, dreams or in the form of flashbacks, 2)
avoidance, which means avoiding reminders of the event, loss of interest and
emotional numbness, and 3) hyperarousal, which is characterised by an ex-
aggerated startle response, hypervigilance and anger in addition to concen-
tration and sleep difficulties [8]. The prevalence of psychiatric conditions
varies greatly between studies, probably due to differences in the methodol-
ogy employed. The most common psychiatric diagnoses are major depres-
sion, which affects 13-23% of burn patients, and PTSD, which is exhibited
by 13-45% [103]. A recent Swedish study using a structured clinical inter-
view for DSM-IV Axis I disorders found that 17 % had major depression
and 9 % fulfilled the criteria for PTSD 12 months after the burn [31].

Community reintegration

Community integration refers to the patients’ ability to function in the home,
in society and with respect to productivity. Previous research suggests that
individuals with burns have significant difficulties especially in terms of
social integration and productivity [32]. Returning to work is an important
milestone for the patients. In a literature review, 90 % of the patients had
returned to some form of work two years after the burn [16], while in an-
other study, 69 % had returned to work 1-6 years after the injury [29]. Those
who had returned to work exhibited better burn-specific health [29, 74] and a
higher quality of life [29].

Risk factors

Injury and socio-demographic characteristics

More severe burns [59, 74, 99] and burns localised to the hands [74, 80, 99]
are risk factors for poorer perceived health. More severe burns are also asso-
ciated with lower return to work [29]. One study showed that physical seque-
lae after major burns are a risk factor for PTSD [69], while another study
found post-burn disfigurement to be a predictor of psychiatric illness [65].
Female gender [59, 74], higher age [30, 58, 74, 99] and living alone [59, 74,
80] are also factors generally associated with a poorer outcome.

Psychiatric morbidity prior to the burn

Psychiatric morbidity prior to the burn is common and significantly more
prevalent than in the normal population [38]. In a recent Swedish study, 66
% of burn survivors had suffered from a psychiatric disorder at some point
during their life before the burn. The most common diagnosis was major
depression (41%) [31]. Patients with psychiatric morbidity prior to the burn
have longer stays in hospital, poorer wound healing [100] and a higher risk of post-burn psychiatric morbidity [31, 38].

**Personality traits**

The World Health Organisation (WHO) defines personality as “*general mental functions of constitutional disposition of the individual to react in a particular way to situations, including the set of mental characteristics that makes the individual distinct from others*” [108]. It has been shown that personality traits are relatively stable over time [44, 87] and that life events have little effect when it comes to personality changes [21].

According to one of the most influential traditions in personality research today, personality can be described by means of five broad domains: Neuroticism, Extraversion, Openness, Agreeableness and Conscientiousness. This five-factor model is based on a lexical and factor analytic approach [21]. Biologically oriented personality theorists view personality as a dimensional and hierarchical structure. For instance Eysenck presented a three-factor model of personality encompassing Extraversion, Neuroticism and Psychoticism [34]. Based on several theories from the biological tradition, Schalling developed the self-report instrument Karolinska Scales of Personality (KSP) that focused on measuring vulnerability for psychiatric illness and psychosocial deviation [93]. Later revisions of the KSP resulted in the Swedish universities Scales of Personality (SSP), which like the KSP, does not attempt to describe the whole personality [43]. A factor analysis of the SSP in the general population indicated that there are three broad domains, Neuroticism, Extraversion and Aggressiveness [43]. These domains were in part supported in a study of former burn patients, where once again three domains were found, namely Neuroticism, Sensation seeking and Aggressiveness [112].

Neuroticism denotes proneness to anxiety, submissiveness, vulnerability to stress and hostility. Neuroticism-related personality traits have been associated with poorer physical and psychological health in general [78] and in patients with burns [29, 36, 37, 60, 63, 110].

Sensation seeking involves impulsiveness and adventure seeking, which denotes acting on the spur of the moment and avoiding routines. It has not been associated with outcome following burns in previous investigations [29, 60, 113], although impulsiveness was found to be overrepresented in former burn patients [112].

The Aggressiveness domain consists of traits indicating verbal and physical aggressiveness and less social conformity or friendliness. The latter is expressed as low scores on the Social desirability subscale. Social desirability indicates a tendency to present oneself in a favourable light and is related to social adjustment and need for approval [70]. Respondents who had high scores in the area of Social desirability appeared to emphasise physical complaints [25] and high scores were found to be more common in chronic pain
patients than in normative samples [56] and healthy volunteers [115]. Furthermore, Social desirability has been associated with fewer psychological symptoms in surgical patients [82] but has not been evaluated in relation to perceived health or use of healthcare in patients with burns.

**Healthcare utilisation**

There is limited research regarding the long-term need for and utilisation of health care after severe burn injury. Furthermore, it is not clear which post-burn problems motivate patients to make further contact with the healthcare services. Previous research has mainly focused on psychological support services after burn injury. In a small scale study it was observed that psychological difficulties may remain undetected in routine follow ups by medical staff. These patients also reported a lack of psychological support [114]. In another small scale study of 42 former patients, almost 40% had psychological problems, about half of whom, a total of 20 %, needed psychological help 18 months after discharge. Half of those, in turn, did not seem to obtain the help they required [35]. In yet another study, 38 % of patients with burns visiting outpatient clinics considered that they would benefit from professional help for their emotional problems [61]. It has also been reported that a substantial fraction of previous patients with burns would utilise a specific multi-professional post-burn service if it were available. The self-reported need for such a service was associated with more physical and psychological symptoms [102]. Considered together, there are indications that the perceived need is greater than the actual utilisation of care in this group of patients.

**Patient satisfaction**

Patient satisfaction with care is a multidimensional concept that has become an important health care outcome. A meta-analysis of satisfaction with medical care revealed the following aspects: overall quality, humaneness, competence, information, organisation, facilities, attention to psychosocial problems, continuity and outcome of care [45]. Other researchers have found similar categories, but with slightly different labels [88]. In a large Norwegian study of patients undergoing various forms of surgery, four dimensions of patient satisfaction were identified: the quality of contact with the nursing staff, the quality of contact with the medical staff, the provision of adequate treatment information and global satisfaction with treatment [95]. Patient satisfaction with care may depend on several individual factors such as personality traits [95], age [46, 51, 54, 116], gender [51] and education [24, 46]. A better health status is associated with higher satisfaction [88, 116]. Expec-
tations before the hospital stay may also be of importance [66, 71, 95, 97] especially regarding satisfaction with nursing care [55].

Patients who are satisfied with the care are more likely to be active and thus have a better chance of improving their health status [4]. This aspect may be crucial for burn patients because of the importance of following treatment regimens after discharge. The way in which burn patients deal with skin care and physiotherapy after discharge is of importance for the outcome [94]. At the time of this investigation, there were no previous studies dealing with multidimensional patient satisfaction with burn care.
Background and aims of the study

The Burn Unit at Uppsala University Hospital is one of two national burn units in Sweden. The catchment area is the middle and northern parts of Sweden with a population of approximately 3 million inhabitants.

This thesis is a part of a multidisciplinary research programme at the Burn Unit. The research was implemented as a joint project between the Burn Unit, the Department of Surgical Sciences, Plastic Surgery, and the Department of Neuroscience, Psychiatry at Uppsala University. Previous doctoral theses from the research group have described the development of burn-specific health and coping measures, the influence of pre-burn psychiatric morbidity and personality traits, cognitive processes, return to work, the presence of itching, nightmares and post-burn psychiatric problems, as well as acceptance of a trauma-related survey [28, 57, 64, 109]. In a wider perspective, the work of the research group aims to deepen the knowledge of how different physical, psychological, injury and care-related aspects influence the outcome after severe burns. The figure below (Figure 1) contains a theoretical model of how a trauma may affect an individual. Every person carries a history of genetic and environmental factors, as well as individual characteristics, e.g. health status, psychological and social factors and probably several unknown factors. During acute care and rehabilitation following a burn, the patient is affected by repeated pain and stressful events. The combination of preburn characteristics, the burn itself and acute burn care has an impact on the rehabilitation process.

The present thesis is a continuation of previous studies by the research group concerning perceived health after burn and its aim is to investigate patients’ experiences of and satisfaction with care and care utilisation during the rehabilitation phase.
The specific aims were to

- describe the perceived need for, and use of, healthcare among former severely burned patients with indications of health problems and to explore possible predictors of healthcare utilisation (Paper I);

- investigate the association between the personality trait of Social desirability and self-reported psychological and physical health (Paper II);

- investigate the former patients’ experiences of burn care by exploring
  - recollections of negative emotional care experiences (Paper III),
  - associations between patient satisfaction with care and socio-demographic and injury-related variables, personality traits, psychological symptoms and perceived post-burn health (Paper IV),
  - predictors of patient satisfaction (Paper V).
Methodology

Participants and procedures

The papers in this thesis are based on three different samples of burn patients treated in the Burn Unit at Uppsala University Hospital. Paper I concerns an investigation of a group of patients treated between 1980 and 1995. Papers II and IV are based on an investigation of former patients treated between 1996 and 2000. Papers III and V take the form of a prospective study of all consecutive adult patients admitted to the Burn Unit from March 2000 to October 2003 and from March 2000 to November 2006 respectively. Socio-demographic and burn-related data for the participants are presented in Table 1.

The 1980 – 1995 cohort

In 1996 all former patients who had been treated in the Burn Unit in Uppsala from 1980 to 1995 were identified. The purpose was to examine their post-burn health status. Those who were ≥ 18 years of age at time of enquiry, had a burn size ≥ 10 % of TBSA burned or Length of Stay (LOS) ≥ 7 days were included. Patients with dementia, serious neurological disorder or severe psychiatric problems were excluded. A total of 350 former patients fulfilled the criteria, but 16 of them could not be located, thus the remaining 334 were sent a questionnaire by post. The questionnaire contained 94 items from the Abbreviated Burn Specific Health Scale (BSHS-A) [76] and the Revised Burn Specific Health Scale (BSHS-R) [14], in addition to socio-demographic questions. Two hundred and forty eight previous patients (74%) returned the questionnaire. Socio-demographic and burn-related characteristics are presented in Tables 1 and 2.

One particular aim was to identify former burn patients with one or more significant health problems. Therefore, a detailed review was conducted of available medical records and the questionnaire responses of each subject. Based on clinical reasoning, a multi-disciplinary team identified participants who could be expected to have health problems as a result of the burn. The review process was performed by two burn surgeons (one at a time), a rehabilitation medicine physician and a burn care nurse. If one or more of the
reviewers considered that a former patient had a clinically significant health problem, he/she was selected for a home visit. Of the 248 responders, 109 were selected (Paper I) for a home visit, the intention of which was to make a more detailed assessment. Five of the former patients died before the visit and 35 declined or were impossible to contact by post or telephone. The remaining 69 individuals, 53 males and 16 females, were visited in their homes by one or two members of the multidisciplinary team.

Table 1. Socio-demographic characteristics of the participants.

<table>
<thead>
<tr>
<th>Paper</th>
<th>Cohort</th>
<th>Total n&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Included n&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Male/Female</th>
<th>Age at time of injury&lt;sup&gt;c&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>1980 – 1995</td>
<td>248</td>
<td>69 (28%)</td>
<td>53/16</td>
<td>37.2 (16.9)</td>
</tr>
<tr>
<td>II</td>
<td>1996 – 2000</td>
<td>116</td>
<td>84 (72%)</td>
<td>62/22</td>
<td>42.6 (16.8)</td>
</tr>
<tr>
<td>III</td>
<td>2000 – 2003</td>
<td>63</td>
<td>42 (67%)</td>
<td>34/8</td>
<td>42.6 (16.8)</td>
</tr>
<tr>
<td>IV</td>
<td>1996 – 2000</td>
<td>116</td>
<td>86 (74%)</td>
<td>63/23</td>
<td>43.0 (17.2)</td>
</tr>
<tr>
<td>V</td>
<td>2000 – 2006</td>
<td>103</td>
<td>69 (67%)</td>
<td>54/15</td>
<td>43.4 (14.6)</td>
</tr>
</tbody>
</table>

<sup>a</sup> Eligible patients  <sup>b</sup> Response rate as a percentage of the total sample within parenthesis  <sup>c</sup> years

Table 2. Burn-related characteristics of the participants.

<table>
<thead>
<tr>
<th>Paper</th>
<th>Time since injury&lt;sup&gt;a&lt;/sup&gt;</th>
<th>TBSA burned&lt;sup&gt;b&lt;/sup&gt;</th>
<th>TBSA-FT&lt;sup&gt;c&lt;/sup&gt;</th>
<th>LOS&lt;sup&gt;d&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>8.2 (4.7)</td>
<td>30.0 (18.3)</td>
<td>9.4 (9.0)</td>
<td>38.0 (30.3)</td>
</tr>
<tr>
<td>II</td>
<td>3.6 (1.2)</td>
<td>17.4 (14.4)</td>
<td>8.1 (10.7)</td>
<td>22.0 (22.9)</td>
</tr>
<tr>
<td>III</td>
<td>2.4 (0.8)</td>
<td>23.0 (21.0)</td>
<td>9.2 (14.2)</td>
<td>25.3 (31.7)</td>
</tr>
<tr>
<td>IV</td>
<td>3.6 (1.2)</td>
<td>17.2 (14.3)</td>
<td>8.0 (10.6)</td>
<td>21.8 (22.7)</td>
</tr>
<tr>
<td>V</td>
<td>10 – 14 months post-burn</td>
<td>26.2 (20.8)</td>
<td>11.1 (15.2)</td>
<td>28.1 (35.8)</td>
</tr>
</tbody>
</table>

<sup>a</sup> years  <sup>b</sup> percent  <sup>c</sup> Total Body Surface Area of the Full Thickness Burn (TBSA-FT) percent  <sup>d</sup> days

In 1999, the 248 former patients who had responded to the questionnaire were considered for another study. Those who had been 15 years or older at the time of injury were approached on a second occasion and asked to complete the SSP and questions about coping strategies. The latter questions were not used in this study. Of the 248 patients, 227 fulfilled the new age criterion and were sent the questionnaires by post.

The January 1996 – March 2000 cohort

In October 2001 (Papers II and IV), patients treated in the Burn Unit from January 1996 to March 2000 were included provided they were > 18 years of age at the time of the investigation, Swedish speaking and with no cognitive dysfunction or dementia. Out of 161 patients admitted, 37 had died during care or after discharge, two had dementia and six had no known address. The remaining 116 patients were sent a questionnaire booklet and a response envelope. Eighty-six returned the booklet, of whom 84 answered the questions about Social desirability required for the study in Paper II. All 86 re-
sponders answered the questions about patient satisfaction required for Paper IV.

The March 2000 – November 2006 cohort

A prospective, longitudinal study was initiated in March 2000. Participants were included providing they were ≥ 18 years of age, Swedish speaking, had no cognitive dysfunction, and had a TBSA burned ≥ 5% or LOS in the Burn Unit of > one day. Patients who were temporarily admitted and had their main care provided elsewhere were not included.

Paper III was based on a study performed in 2004 as part of this longitudinal study. Out of 63 patients who fulfilled the criteria, ten declined participation in the longitudinal study and a further ten in the present study. In addition, one patient was excluded due to ongoing psychotic symptoms. The remaining 42 participants received information about the study by post, and oral consent was obtained by telephone, after which they were randomised into three groups: postal questionnaire, telephone interview and face-to-face interview.

Paper V was based on the same prospective longitudinal study and inclusion criteria as described above. The participants were included from March 2000 to November 2006. One hundred and three patients fulfilled the criteria, five were omitted due to administrative reasons and 17 declined participation. Data collection pertaining to possible predictors of patient satisfaction was performed during their treatment in the Burn Unit. Data collection regarding patient satisfaction was performed immediately after a 12 month post-burn clinical visit. Eleven failed to return the patient satisfaction questionnaire and thus could not be followed-up. Furthermore, one of the included patients died during the first year, leaving 69 participants (68%).

Assessments and measures

Health

The Burn Specific Health Scale-Brief (BSHS-B) used in papers I, II, and IV is a 40-item questionnaire measuring perceived function and wellbeing [58]. It consists of nine subscales reflecting different aspects of health: Simple abilities, Hand function, Heat sensitivity, Treatment regimens, Body image, Affect, Interpersonal relationships, Sexuality and Work. The items were rated on a five-point scale from 0 = “all the time/great difficulty” to 4 = “never/no difficulty”. Mean scores were calculated for the nine subscales. Cronbach’s alpha ranged between 0.75 and 0.93 in the original study [58], suggesting good internal consistency. In a recent study, the BSHS-B was
subjected to a second-order factor analysis yielding three intelligible factors; Function, Skin involvement and Affect and relations [111].

Care utilisation and perceived needs
Previous and current care utilisation and needs, as well as current functional restrictions were assessed by means of a semi-structured interview.

Personality traits
Personality traits were assessed using the SSP [43], which is a 91-item inventory containing 13 subscales each of which comprises seven items: 1) Somatic trait anxiety, 2) Psychic trait anxiety, 3) Stress susceptibility, 4) Lack of assertiveness, 5) Detachment, 6) Embitterment, 7) Mistrust, 8) Trait irritability, 9) Impulsiveness, 10) Adventure seeking, 11) Social desirability, 12) Verbal trait aggression and 13) Physical trait aggression. The items were rated on a scale of 1 = “Does not apply at all” to 4 = “Applies completely”. The SSP has been standardised into T-scores with means of 50 and Standard Deviations (SD) of 10 in a Swedish age- and sex-stratified non-patient sample [43, 112]. In previous studies of former burn patients, Cronbach’s alpha values for the 13 subscales ranged between 0.66 and 0.85 [60], and the three domains had values of 0.90 for Neuroticism (subscales 1-8), 0.70 for Sensation seeking (subscales 9-10) and 0.65 for Aggressiveness (subscale 11 reversed scoring and 12-13) [112].

Patient experiences of care
The Patient Satisfaction-Results and Quality (PS-RESKVA) instrument was developed in Norway by means of large scale studies carried out after surgical care [42, 95] (Papers IV and V). It contains 39 items of which 27 are included in four subscales (Table 3). Each item from the PS-RESKVA questionnaire was scored on a scale from 0 = “Not at all”, to 4 = “Very much”. Average scores were calculated for each subscale. The Cronbach’s alpha values for the subscales varied between 0.63 and 0.81 (Paper V).

Negative emotional experiences
Recollection of negative emotional experiences was assessed by means of six questions (Table 4) based on empirical findings related to patient experiences of the ICU environment and burn care [6, 79, 89] and inspired by patient reports in the longitudinal study conducted in the Uppsala Burn Unit.
Table 3. The PS-RESKVA subscales, labels and content.

<table>
<thead>
<tr>
<th>PS-RESKVA Subscales</th>
<th>Abbreviation</th>
<th>Description of subscale</th>
<th>Number of items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of contact</td>
<td>QCN</td>
<td>Confidence in professional skills, continuity, involvement, communication (time for and</td>
<td>8</td>
</tr>
<tr>
<td>with nursing staff</td>
<td>QCM</td>
<td>understandable communication), staff have time to help</td>
<td></td>
</tr>
<tr>
<td>Quality of contact</td>
<td>INF</td>
<td>Information about medication, self-care and prevention, preparation for discharge</td>
<td>6</td>
</tr>
<tr>
<td>with medical staff</td>
<td>GS</td>
<td>Satisfaction with treatment, time for discharge, importance of treatment, fulfilled</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>expectations regarding medical care, and information about examinations and tests</td>
<td></td>
</tr>
</tbody>
</table>

Table 4. Questions assessing negative emotional care experiences.

<table>
<thead>
<tr>
<th>Item</th>
<th>Short title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you feel certain that you would get well again?</td>
<td>Uncertainty</td>
</tr>
<tr>
<td>Did you feel powerless and dejected?</td>
<td>Powerlessness</td>
</tr>
<tr>
<td>Were you afraid that you would not make it?</td>
<td>Afraid</td>
</tr>
<tr>
<td>Did you feel safe in the ward?</td>
<td>Insecurity</td>
</tr>
<tr>
<td>Did you feel that you were a nuisance in the ward?</td>
<td>Nuisance</td>
</tr>
<tr>
<td>When you needed assistance in the ward, did you have to wait a long time before anyone came?</td>
<td>Neglected</td>
</tr>
</tbody>
</table>

Psychological symptoms

Symptoms of anxiety and depression were assessed by means of the Hospital Anxiety and Depression Scale (HADS). The instrument has been developed for use in non-psychiatric patients and consists of two subscales, Anxiety and Depression, each with 7 items, all of which are rated on a scale from 0 = “no symptom” to 3 = “severe symptom” [117]. Previous studies have shown good psychometric properties in various groups [11, 117].

Symptoms of PTSD were assessed by means of the Swedish version of the Impact of Event Scale-Revised (IES-R). The instrument has 22 items divided into three subscales; Intrusion, Avoidance, and Hyperarousal [105]. The scores 0, 1, 3 and 5 from the original Impact of Event Scale (IES) were used, where “0” equals no symptom and “5” equals high frequency of the symptom [49]. Previous studies have revealed the IES to have good psychometric properties [98], while the original IES-R has been shown to have less stable factors but good internal consistency [22].
Socio-demographic and burn-related variables

Age, gender and variables related to injury severity and treatment were taken from medical records, while marital status, length of education and duration of burn-related sick-leave were collected by questionnaire. The burn-related variables used in the different papers are presented in Table 5.

Table 5. Burn-related variables

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>TBSA burned</td>
<td>TBSA burned</td>
<td>TBSA burned</td>
<td>TBSA burned</td>
<td>TBSA burned</td>
</tr>
<tr>
<td>TBSA FT</td>
<td>LOS</td>
<td>LOS</td>
<td>TBSA FT</td>
<td>TBSA FT</td>
</tr>
<tr>
<td>LOS</td>
<td>Time since injury</td>
<td>Time since injury</td>
<td>Time since injury</td>
<td>Days on ventilator</td>
</tr>
<tr>
<td>Time since injury</td>
<td>Length of burn-related sick leave</td>
<td>Length of burn-related sick leave</td>
<td>Length of burn-related sick leave</td>
<td>Days off ventilator</td>
</tr>
</tbody>
</table>

Statistical analyses

The analyses used in Papers I-V are summarised in Table 6. Group comparisons were studied by means of Student’s independent t-test for two groups and Analysis of Variance (ANOVA) for comparisons involving three groups. In the case of not normally distributed data, the Mann-Whitney U-test and Kruskal-Wallis test were used. In Papers IV and V, paired t-tests with Bonferroni correction were used for comparisons between the mean scores of the PS-RESKVA subscales.

Categorical data were analysed using chi-square and the Fisher exact test was employed when the expected number of observations in a cell was less than 5. For continuous data, associations were assessed by means of the Pearson correlation coefficient or, in the case of non-normality, Spearman rank correlation. Associations were also studied by use of regression analysis (Papers I, IV and V). In paper I, the dependent variable, current care contact, was dichotomous and therefore logistic regression was used in accordance with the principles recommended by Hosmer & Lemeshow [50]. First the independent variables were evaluated by means of simple logistic regressions. Those with p-values < 0.25, which amounted to 19, were subsequently included in backward, stepwise multiple logistic regressions. In these and the final regression, p< 0.05 was considered statistically significant.

In Papers IV and V the dependent variables were the four PS-RESKVA subscales, thus linear multiple regression was used (backwards exclusion, F-to-enter p < 0.05, F-to-remove p < 0.1).
Table 6. Statistical methods

<table>
<thead>
<tr>
<th>Paper</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Student’s t-test</td>
</tr>
<tr>
<td></td>
<td>Mann Whitney U-test</td>
</tr>
<tr>
<td></td>
<td>Logistic regression</td>
</tr>
<tr>
<td>II</td>
<td>Pearson correlation coefficients</td>
</tr>
<tr>
<td></td>
<td>Student’s t-test</td>
</tr>
<tr>
<td></td>
<td>ANOVA</td>
</tr>
<tr>
<td></td>
<td>Chi-square</td>
</tr>
<tr>
<td></td>
<td>Fischer’s exact test</td>
</tr>
<tr>
<td></td>
<td>Spearman’s rank correlations</td>
</tr>
<tr>
<td></td>
<td>Kruskal-Wallis test</td>
</tr>
<tr>
<td></td>
<td>Mann Whitney U-test</td>
</tr>
<tr>
<td>III</td>
<td>Chi-square</td>
</tr>
<tr>
<td></td>
<td>Mann Whitney U-test</td>
</tr>
<tr>
<td></td>
<td>Spearman’s rank correlations</td>
</tr>
<tr>
<td></td>
<td>ANOVA</td>
</tr>
<tr>
<td>IV</td>
<td>Chi-square</td>
</tr>
<tr>
<td></td>
<td>Student’s t-test</td>
</tr>
<tr>
<td></td>
<td>Pearson correlation coefficients</td>
</tr>
<tr>
<td></td>
<td>Multiple regression</td>
</tr>
<tr>
<td>V</td>
<td>Chi-square</td>
</tr>
<tr>
<td></td>
<td>Student’s t-test</td>
</tr>
<tr>
<td></td>
<td>Simple and multiple regressions</td>
</tr>
</tbody>
</table>

Several steps were taken in Papers IV and V in order to avoid the inclusion of too many independent variables. Firstly, separate regressions for groups of independent variables preceded the final regression models. Secondly, in Paper IV, the three SSP domains were used instead of the 13 separate sub-scales, and LOS was chosen as the only indicator of injury severity. Longer stays in hospital increase exposure to burn care and may be more influential than extent of injury in terms of satisfaction ratings.

The adjusted $R^2$ was used as a measure of explained variance in Papers IV and V.

Ethics

All studies were performed according to the principles of the Helsinki Declaration [1] and approved by the Ethics Committee of Uppsala University.
Results

Use of healthcare a long time after severe burn injury (Paper I).

In general, eight years after the injury, half of the former patients were in contact with the healthcare services due to their burn, and the general practitioner (GP) was the most common care contact. Functional restrictions were common and the most frequent problems were skin-related. Nine former patients reported psychological difficulties as the worst perceived problem.

There were no significant differences regarding socio-demographic variables or injury characteristics between those who were and those who were not in contact with the healthcare services at the time of the investigation. Those receiving care had significantly lower burn-specific health in three of the BSHS-B domains: Simple abilities, Work, and Hand function. Furthermore, they scored significantly higher on the SSP-scales Stress susceptibility and Lack of assertiveness and lower on Social desirability. They also scored significantly higher in the SSP-domain of Neuroticism, which contains eight of the SSP-sub scales (e.g. Stress susceptibility and Lack of assertiveness). For the purpose of this summary, intercorrelations were calculated for the BSHS-B and SSP subscales. In the present sample, the three BSHS-B subscales had intercorrelations that varied between 0.39 and 0.52. The intercorrelation between Stress susceptibility and Lack of assertiveness was $r = 0.63$, while the intercorrelations with Social desirability were $r = -0.19$ and $r = -0.08$, respectively.

In logistic regressions, current utilisation of healthcare was associated with Simple abilities, Stress susceptibility and Adventure seeking, and $R^2$ was 0.33. Assuming the biological importance of TBSA-FT, this variable was subsequently forced into the final equation. The strength of association with current healthcare utilisation increased to 0.41.

At the time of the writing of the manuscript, the statistical software used had limited capacity to process logistic regressions. A more recent statistical application with superior capacity is the Statistical Package for the Social Sciences (SPSS). All analyses in Paper I have therefore been re-analysed using the SPSS. The final logistic regression model was identical to the previous one. The Nagelkerke $R^2$, which is an approximation of the strength of association given in SPSS, was 0.48 for the three independent variables and 0.58 when TBSA-FT was forced into the equation.
Social desirability, psychological symptoms and perceived health in burn injured patients (Paper II).

The mean Social desirability score was close to the Swedish norm for the whole group (mean = 50, SD = 10). Women had significantly higher Social desirability scores than men. Social desirability was not related to socio-demographic or injury-related variables, or the presence of documented psychiatric problems. There were no significant correlations detected between Social desirability and the HADS, IES-R or BSHS-B.

The participants were divided in three groups, those with 1) normal (range of T-scores 40–60), 2) low (T-scores < 40) and 3) high Social desirability scores (T-scores > 60). The cut off values were based on the standard deviation of the T-distribution (Mean = 50, SD = 10.0). Group differences were observed for three BSHS-B subscales: Heat sensitivity (Kruskal-Wallis H[2] = 7.3; p < 0.05), Work (H[2] = 6.2; p < 0.05) and Body image (H[2] = 7.2; p < 0.05). Post hoc analyses revealed that those with high Social desirability scores reported a lower health status than those with normal scores.

On inspection, the average ranks suggested a nonlinear relationship between Social desirability and health for Heat sensitivity (low = 40.6, normal = 47.1, high = 29.0), Work (low = 34.6, normal = 47.2, high = 32.9) and Body image (low = 38.9, normal = 46.8, high = 29.0).

Evaluation of negative emotional care experiences in burn care (Paper III).

Overall, the participants reported low levels of negative emotional care experiences. The distribution of responses showed that the whole range was used, except for the items Afraid and Insecurity; i.e. none of the patients had felt afraid or insecure all the time. The most common negative experience was Powerlessness, with 67% reporting feeling powerless to some degree.

The item Afraid was significantly associated with injury severity variables, such as number of days on respiratory support, i.e. mechanical ventilation, the extent of TBSA-FT and LOS. The item Powerlessness was associated with TBSA burned and LOS. Moreover, there was a negative association between Nuisance and Time since injury.

The analyses of relationships with patient satisfaction revealed that Insecurity was negatively associated with Quality of contact with the medical staff and Nuisance was negatively associated with Quality of contact with the nursing staff.

Symptoms of PTSD assessed by means of the IES-R total score correlated positively with the item Powerlessness. There were no associations between
negative emotional care experiences and personality domains, the HADS, gender, age, marital status, education or income.

Patient satisfaction with burn care 1-6 years after injury (Paper IV).

Most previous patients reported good satisfaction with care. The mean scores ranged between 1.8 and 3.3 for the PS-RESKVA subscales. In paired comparisons of mean scores, the participants rated satisfaction with the nursing staff higher than other aspects of care, while Adequate treatment information attained the lowest scores (all p-values < 0.001). The mean scores for Global satisfaction with treatment and Quality of contact with the medical staff did not differ.

Regression analyses revealed that patient satisfaction was moderately correlated with health and individual characteristics. The results from the final multiple regressions are presented in Table 7. In the final Quality of contact with the nursing staff model, Expectations of being healthy, Expectations of good care and nursing, the BSHS-B Interpersonal relationships and Sensation seeking subscales and Time since injury explained 25 % of the variance. For Quality of contact with the medical staff, two SSP-domains Sensation seeking and Aggressiveness as well as the BSHS-B Interpersonal relationships and Heat sensitivity subscales, Age at time of injury and Marital status explained 18 % of the variance. In the final Adequate treatment information model, the SSP Sensation seeking domain, the BSHS-B Interpersonal relationships subscale, in addition to Age at injury and LOS explained 19 % of the variance. Finally, for Global satisfaction, two SSP domains; Sensation seeking and Aggressiveness, the BSHS-B Interpersonal relationships subscale and Time since injury explained 22 % of the variance.

Thus, the BSHS-B Interpersonal relationships subscale was represented in all of the final models, while the SSP Sensation seeking and Aggressiveness domains contributed significantly to two of the four models.

Prediction of patient satisfaction with care one year after burns (Paper V).

In this prospective study, most previous patients were highly satisfied with the care. The mean scores for the PS-RESKVA subscales varied between 2.1 and 3.5. As in the cross sectional study described above (Paper IV), paired comparisons of mean scores revealed that the participants rated satisfaction with the nursing staff higher than other aspects of the care. Again, the Adequate treatment information subscale attained the lowest scores (all p-values
Table 7. The final multiple regression models with PS-RESKVA subscales as dependent variables.

<table>
<thead>
<tr>
<th>Subscale</th>
<th>F-value</th>
<th>β</th>
<th>t-value</th>
<th>p-value</th>
<th>Adj. R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of contact with the nursing staff</td>
<td>6.2</td>
<td></td>
<td></td>
<td>&lt; 0.0001</td>
<td>0.25</td>
</tr>
<tr>
<td>Expectations of becoming healthy</td>
<td>0.18</td>
<td>1.7</td>
<td>&lt; 0.10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expectations of good care and nursing</td>
<td>0.29</td>
<td>2.8</td>
<td>&lt; 0.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BSHS-B: Interpersonal relationships</td>
<td>0.26</td>
<td>2.1</td>
<td>&lt; 0.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BSHS-B: Sexuality</td>
<td>-0.31</td>
<td>-2.6</td>
<td>&lt; 0.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time since injury</td>
<td>0.20</td>
<td>1.9</td>
<td>&lt; 0.10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of contact with the medical staff</td>
<td>3.9</td>
<td></td>
<td></td>
<td>&lt; 0.01</td>
<td>0.18</td>
</tr>
<tr>
<td>SSP: Sensation seeking</td>
<td>0.20</td>
<td>1.7</td>
<td>&lt; 0.10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSP: Aggressiveness</td>
<td>-0.26</td>
<td>-2.2</td>
<td>&lt; 0.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BSHS-B: Interpersonal relationships</td>
<td>0.24</td>
<td>2.1</td>
<td>&lt; 0.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BSHS-B: Heat sensitivity</td>
<td>-0.23</td>
<td>-2.0</td>
<td>&lt; 0.10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at time of injury</td>
<td>0.18</td>
<td>1.7</td>
<td>&lt; 0.10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td>-0.20</td>
<td>-1.9</td>
<td>&lt; 0.10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adequate treatment information</td>
<td>5.5</td>
<td></td>
<td></td>
<td>&lt; 0.01</td>
<td>0.19</td>
</tr>
<tr>
<td>SSP: Sensation seeking</td>
<td>0.21</td>
<td>2.1</td>
<td>&lt; 0.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BSHS-B: Interpersonal relationships</td>
<td>0.27</td>
<td>2.5</td>
<td>&lt; 0.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at time of injury</td>
<td>-0.28</td>
<td>-2.7</td>
<td>&lt; 0.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LOS</td>
<td>0.33</td>
<td>3.1</td>
<td>&lt; 0.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Global satisfaction with treatment</td>
<td>6.5</td>
<td></td>
<td></td>
<td>&lt; 0.001</td>
<td>0.22</td>
</tr>
<tr>
<td>SSP: Sensation seeking</td>
<td>0.24</td>
<td>2.2</td>
<td>&lt; 0.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSP: Aggressiveness</td>
<td>-0.37</td>
<td>-3.4</td>
<td>&lt; 0.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BSHS-B: Interpersonal relationships</td>
<td>0.32</td>
<td>3.2</td>
<td>&lt; 0.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time since injury</td>
<td>0.28</td>
<td>2.8</td>
<td>&lt; 0.01</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

SSP = Swedish universities Scales of Personality, BSHS-B = Burn Specific Health Scale-Brief,

*a 1=married/cohabiting, 0= living alone

Adj. R² = Cumulative adjusted explained variance. F to enter p< 0.05, F to remove p< 0.1

< 0.001), while the mean scores for Global satisfaction with treatment and Quality of contact with the medical staff did not differ.

In general, patient satisfaction was poorly, but still significantly, predicted by age and education, symptoms of PTSD and personality traits related to stress and interpersonal relations. The results of the final models can be seen in Table 8. In the final Quality of contact with the nursing staff model, two stress-related variables, the IES-R Intrusion subscale and the SSP Stress susceptibility subscale explained 14 % of the variance. In the Quality of contact with the medical staff model, 19 % of the variance was explained by Age at time of injury, Education and the IES-R Hyperarousal subscale. In the final Adequate treatment information model, the SSP Trait irritability
Table 8. Prediction models for patient satisfaction with care.

<table>
<thead>
<tr>
<th>Predictive variables</th>
<th>F-value</th>
<th>β</th>
<th>t-value</th>
<th>p-value</th>
<th>Adj. R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of contact with the nursing staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Final model</td>
<td>6.3</td>
<td>0.003</td>
<td>2.81</td>
<td>0.007</td>
<td>0.14</td>
</tr>
<tr>
<td>IES-R Intrusion</td>
<td>0.34</td>
<td>2.81</td>
<td>0.007</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSP Stress susceptibility</td>
<td>-0.36</td>
<td>-2.94</td>
<td>0.005</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of contact with the medical staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Final model</td>
<td>6.1</td>
<td>0.001</td>
<td>2.78</td>
<td>0.007</td>
<td>0.19</td>
</tr>
<tr>
<td>Age at time of injury</td>
<td>0.32</td>
<td>2.78</td>
<td>0.007</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>-0.22</td>
<td>-1.89</td>
<td>0.063</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IES-R Hyperarousal</td>
<td>0.22</td>
<td>1.99</td>
<td>0.051</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adequate treatment information</td>
<td>4.9</td>
<td>0.031</td>
<td>2.36</td>
<td>0.021</td>
<td></td>
</tr>
<tr>
<td>SSP Trait irritability</td>
<td>-0.27</td>
<td>-2.21</td>
<td>0.031</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Global satisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Final model</td>
<td>4.6</td>
<td>0.006</td>
<td>1.73</td>
<td>0.09</td>
<td>0.14</td>
</tr>
<tr>
<td>SSP Detachment</td>
<td>-0.21</td>
<td>-1.72</td>
<td>0.09</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSP Social desirability</td>
<td>0.21</td>
<td>1.73</td>
<td>0.09</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at time of injury</td>
<td>0.27</td>
<td>2.36</td>
<td>0.021</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

SSP = Swedish universities Scales of Personality, IES-R = Impact of Event Scale-Revised
Adj. R² = Cumulative adjusted explained variance.
F to enter p< 0.05, F to remove p< 0.1

The total amount of explained variance was low in all four models, indicating that other variables affect satisfaction with care. This strengthens the hypothesis that the care itself makes a more substantial contribution to satisfaction than individual factors.
Discussion

The overall aims of this thesis were to describe and explore care utilisation, health outcome and the patients’ experiences of burn care. Several possible concurrent and/or predictive factors were explored, e.g. socio-demographic and injury characteristics, physical and psychological symptoms in addition to the patients’ individual characteristics. Overall, interpersonal aspects exerted a greater influence than injury characteristics.

Care utilisation and perceived health after burns

Adaptation after a major physical injury is a complex process that takes time. Patients with burns who require specialised care must undergo rehabilitation for an extended period. Paper I is one of a small number of studies of care utilisation in former patients with burns and is unique, with respect to the long time after injury.

Burn-specific health

As described in Paper I, half of the subjects with identified health problems had contact with the healthcare services due to their burns on average eight years after the injury. They reported poorer functioning in terms of Simple abilities, Hand function and Work in the BSHS-B. The items that form the Simple abilities and Hand function subscales concern every-day tasks such as being able to dress oneself and pick up coins from a flat surface, and it is likely that such abilities are associated with the ability to work. The BSHS-B Work subscale mainly assesses the perceived impact of the burn on the ability to work. In this selected sample, the intercorrelations between the subscales were moderate to fairly strong and a recent publication by the research group suggests that the three subscales reflect a common theme [111]. In the study, the BSHS-B was subjected to a second-order factor analysis, in which the three subscales loaded on the same factor, labelled “Function”. However, for statistical and conceptual reasons, the study finally indicated that the Work subscale should be viewed as an outcome domain in itself. Thus, care utilisation among former patients with identified health problems is mainly
associated with problems in the Function domain, as opposed to the other BSHS-B domains associated with affective and skin-related problems.

**Personality traits**

**Neuroticism**

Those who had contact with the healthcare services at the time of the study reported higher Stress susceptibility, Lack of assertiveness and a higher mean score in the Neuroticism domain as determined by the SSP personality inventory. Stress susceptibility implies a tendency to become easily fatigued and Lack of assertiveness denotes inability to speak up in social situations, both of which are parts of the SSP Neuroticism domain. Although there are no previous studies that focus on personality traits and care utilisation after burns, the findings can be related to investigations in the mental health area. In one epidemiological study including individuals with a recognised psychiatric condition, Self-criticism was associated with more use of outpatient mental health services [72]. In another study, mental healthcare utilisation was consistently negatively associated with Extroversion in the NEO Personality Inventory (NEO-PI), positively associated with Agreeableness, and moderately positively associated with Neuroticism [73].

**Social desirability**

Furthermore, care utilisation was negatively associated with Social desirability, which is defined as a need for approval. Social desirability is part of the SSP domain of Aggressiveness, where it has a reversed scoring. The subscale was adapted from the Marlowe-Crowne Social Desirability Scale (M-C SDS) [23] and contains questions such as “I’m always polite and self-controlled, regardless of whom I talk to”. Thus, individuals who have less need of social approval were more inclined to have care contacts many years after the injury than those with a greater need for approval.

In Paper II, Social desirability was further examined in relation to perceived health in an unselected group of former patients. The results here were in line with previous literature, demonstrating that Social desirability is positively associated with physical health problems [25, 56, 115]. In Paper II, the participants with higher Social desirability scores reported more perceived problems with Heat sensitivity, Body image and Work. The BSHS-B Heat sensitivity subscale assesses perceived skin sensitivity to heat and associated restrictions, e.g. difficulties being outdoors in hot weather. The Body image subscale measures the impact of dissatisfaction with one’s appearance. An interpretation of this finding is that individuals with a high level of Social desirability perceive greater problems in situations involving outdoor
activities and/or social contacts where skin and appearance are more important. As suggested above, work in itself may be such a situation, i.e. a separate outcome domain. In the previously cited second-order factor analysis, Work was highly associated with the factor “Skin involvement” which contains both Heat sensitivity and Body image [111]. The samples in Papers I and II consist of former patients who constituted part of the sample in the cited second-order factor analysis. Hence, these findings are not completely independent and should be replicated by means of a separate sample.

The findings in Papers I and II may seem contradictory, as high Social desirability was associated with less care utilisation (Paper I) and poorer perceived health (Paper II). However, care utilisation is not a reflection of perceived health problems, as indicated by the relatively few associations between health and care utilisation in Paper I. Furthermore, as Paper I is based on results from a selected sample with identified health problems and Paper II is based on an unselected sample, such direct comparisons may be flawed. A tentative suggestion could be that among individuals who have identified health problems many years after the injury, low Social desirability is associated with more persistent help-seeking, which facilitates care utilisation.

Care experiences and patient satisfaction

Optimal goals in nursing care are that the patients will feel security, fearless-ness and participation. Intensive care challenges our basic need for independence and control, and burn care encompasses many painful situations. It was therefore encouraging that the participants reported a low level of negative emotional care experiences (Paper III). The recollections of negative emotional experiences during burn care were not associated with symptoms of general anxiety or depression at the time of the investigation, nor with personality traits. Thus, the results are unlikely to be biased by mood or individual characteristics.

Recollections of feeling powerless were associated with more extensive injuries, a longer stay in hospital and later symptoms of PTSD. Feeling afraid was also associated with more extensive injuries, more days on respiratory support, i.e. mechanical ventilation, and a longer hospital stay. Fear is a common emotional reaction reported by patients in general ICUs [81, 89, 91] and thoracic surgery [41]. These emotional reactions may be related to certain aspects of the ICU situation. Negative experiences frequently recalled by patients are difficulties communicating, being in pain and being restricted by tubes and lines [91]. It is important to minimise these moments of fear, since such experiences have been associated with more PTSD symptoms two months after the ICU stay [92] and with general anxiety and PTSD symptoms up to one year after discharge from the ICU [85, 86]. Moreover,
stressful memories have been previously related to insufficient sedation during mechanical ventilation [91]. In addition, it has been reported that staff who are stressed cause increased stress in patients [101]. In Paper III, the feeling of being a nuisance to staff was negatively associated with later patient satisfaction regarding quality of contact with the nursing staff. Thus, nurses should take care to avoid giving the impression that caring for the patient is a burden.

Feelings of insecurity were negatively associated with Quality of contact with the medical staff, i.e. those who were satisfied with their level of contact with physicians felt more secure. Despite the relatively short period per day of contact between the physician and patient, the results in Paper III suggest that physicians play a key role concerning patient security. A safe, caring ICU environment with adequate information has been found to be important for patient empowerment [101]. Furthermore, support to strengthen the patients’ will to live has been identified as an important task for staff and relatives, and it is valuable for the patient to feel important as a person, not only as a patient [101].

Patient satisfaction

In this thesis, care experiences were also investigated from a more general perspective, namely patient satisfaction with care, which was the focus of Papers IV and V. Patient satisfaction concerns the patient’s opinions about different aspects of care and it has been suggested as an important part of high quality care [27].

Paper IV is the first study to use a multidimensional measure of patient satisfaction in burn care, and paper V is the first to present a prediction of multidimensional patient satisfaction with burn care. In both studies, the mean scores on the PS-RESKVA subscales indicated that many patients were satisfied. In general, high ratings are common in studies of patient satisfaction [97]. The skewed distribution of scores is problematic in statistical analyses and affects the applicability of the results. More specific questions regarding care procedures need to be developed in order to achieve more diversity in responses. In general, the participants rated items concerning the nursing staff higher than other items, while satisfaction with information attained the lowest score. Lower satisfaction with information than with other aspects of care has previously been reported in surgical patients [95]. Age was associated with greater satisfaction with medical staff and predicted Global satisfaction, but was negatively associated with Adequate treatment information. Thus, elderly patients may be more satisfied with staff and procedures, but feel less informed. Overall, the results suggest that there is room for improvement in the area of information routines, especially for elderly patients.
Expectations of care were studied in Paper IV and their sole contribution was in the satisfaction with contact with nursing staff model. This is not in line with the literature, where expectations are usually found to be important [95, 97]. There may be several explanations for this discrepancy. First, in Paper IV the expectations on the care were assessed retrospectively. Second, the expectations reported in most previous studies of surgical care concern elective surgery, while Paper IV concerns acute admissions. Patients undergoing elective surgery have the opportunity to anticipate and develop expectations before admission to the hospital, while those admitted acutely develop such expectations during care, or the reported expectations may be reconstructions after the event.

In the regression models in Papers IV and V, the overall impression is that variables involving aspects of interaction with others had a greater impact than injury characteristics. In Paper IV, this was represented by the variables Interpersonal relationships and Aggressiveness, and in Paper V by four personality traits; Stress susceptibility, Detachment, Trait irritability and Social desirability. The SSP domain of Aggressiveness consists of three subscales, Verbal trait aggression, Physical trait aggression and Social desirability, where the latter has reversed scoring. The associations between patient satisfaction and Aggressiveness in Paper IV were negative, while the association between Social desirability and satisfaction in Paper V was positive which, when taken together, suggests that those with the least aggressive manner were more satisfied. The remaining three personality traits have interpersonal aspects, such as feeling uneasy when urged by others to hurry up (Stress susceptibility), being socially withdrawn (Detachment), and lacking patience with others (Trait irritability).

The importance of interpersonal factors for patient satisfaction has been observed in previous studies. In a study of satisfaction with anaesthesia, satisfaction was predicted by the kindness and regard of caregivers, the information provided by the anaesthetist and feeling safe [17]. The authors concluded that elements of care pertaining to emotional and interpersonal relationships are the most significant from a patient perspective. The importance of interpersonal factors has also been observed in other patient groups. For instance, in a study of patients with diabetes, interpersonal dimensions were more associated with overall satisfaction than were organisational dimensions [106], and in yet another study interpersonal skills had more influence on satisfaction than technical skills in three out of four different patient groups [18]. Satisfaction with staff may be associated with the patients’ ability to interact in general, as well as with previous interpersonal experiences. For example, the perception of being fully supported by the clinical staff after a diagnosis of breast cancer was associated with recalled positive relationships during childhood [90].

In accordance with previous studies [48, 95], the regression analyses in Papers IV and V demonstrated that patient satisfaction was only moderately
associated with health and individual characteristics. This is an encouraging finding, as it implies that the care itself is of major importance for the unexplained variance in patient satisfaction with care. The organisation of care may be one key aspect; for instance, continuity of care provider was strongly associated with higher satisfaction in a longitudinal study of physical therapy [10].

A preliminary conclusion is that the PS-RESKVA instrument is an appropriate tool for evaluating patient satisfaction with burn care.

Methodological considerations and limitations

Study design
This thesis contains studies with retrospective, cross-sectional and prospective research designs. In Papers I and II, which are cross-sectional studies, the long period of time that elapsed between the injury and the assessment is a limitation, as other life events or diseases that may have affected the former patients’ perceived health were not controlled for. At the same time, the long period of time that had elapsed since the injury is a strength, as there are very few long-term evaluations of burn-specific health. Furthermore, in Paper I, the assessment of burn-specific health and the semi-structured interview regarding care utilisation were carried out before the assessment of personality. However, as personality traits have been found to be relatively stable in adulthood, this is unlikely to have created bias in the results.

In Papers I-IV, the cross-sectional design makes it impossible to draw causal conclusions. In Papers III-IV, the recollections of negative emotional care experiences and expectations of care were measured retrospectively. In these studies, the time that had elapsed between care and evaluation may have affected the results, as individuals’ ability to recall their experiences can differ. Studies of the memory have found that stimuli with an emotional content cause stronger memories than neutral stimuli [26]. Thus it can be assumed that the participants’ memories of their time in care were sufficient for a reliable evaluation, since this experience is almost certainly emotionally influenced.

Papers IV and V had a common theme, as both used multiple regression techniques to explain the variance in patient satisfaction. However, as Paper V had a prospective design and a predictive aim, different independent variables were considered. Thus, it is not a true replication of Paper IV and the studies cannot be directly compared.
Samples

A limitation that concerns all papers is the relatively small samples. The incidence of severe burns in Sweden is small. However, in comparison with other burn research, the present studies have a low proportion of non-responders. One reason for this is that all Swedish inhabitants can be identified by their national security numbers and their addresses obtained through a nationwide register.

All papers, with the exception of Paper I, were based on the total number of eligible adult patients with burns treated during the specified time periods. Taken together with the high response rates, the samples can be deemed fairly representative of Swedish patients with burns. In Paper I, the aim was to identify and subsequently study former patients with persistent health problems. The sample was selected by a multiprofessional team using clinical reasoning. This selection process may have been affected by the prejudices of the team members. The process resulted in the inclusion of as many as 44 percent of all individuals treated in the Uppsala Burn Unit, thus over-rather than under-inclusion may be suspected.

Methods

The data collection methods were self-report questionnaires and semi-structured interviews. In general, self-report instruments are considered valuable, although there is a risk of bias in the responses, as the participants may give socially desirable answers and avoid extreme answers [20].

However, interviews may also be biased. In Paper I, the home visits and semi-structured interviews were conducted by a nurse, sometimes together with a plastic surgeon or occupational therapist. All had expertise in burn care. The participants’ awareness of the researchers’ profession may have affected the answers. If the interviewers had been psychologists or psychiatrists, the participants might have reported fewer skin-related problems. Nevertheless, several participants reported psychological problems, which indicates that they did not perceive the focus as being exclusively on physical problems.

The negative emotional care experiences assessed in Paper III were examined by means of items which had not been previously evaluated psychometrically. Such instruments are available today [92], but more validation is necessary before they are used.

Due to the prospective design of paper V and the aim to predict satisfaction with care, the retrospective questions about expectations in the PS-RESKVA were not considered. A different design will be necessary in order to evaluate and predict satisfaction based on the patients’ expectations.

Methodological issues such as the data collection method, length of time since discharge, the number of response alternatives and administration
methods may affect the ratings of satisfaction with care. The literature describes a higher response rate in telephone surveys compared to postal surveys, as well as greater satisfaction among patients still in hospital or discharged several months previously compared to those discharged shortly before the survey [88]. Comparisons between different response formats such as 4, 5 or 6-point scales have been made, but it is still unclear which is preferable [52].

**Implications and future aspects**

A burn injury results in physical, psychological and social problems for the individual [13, 59].

To facilitate the severely burned patients’ recovery and adaptation our results suggest that early screening of personality traits that are associated with an increased vulnerability, and as suggested by others [31], assessment of psychiatric morbidity would be of value. Both the SSP and the SCID-I used in those studies are rather extensive instruments. There is a need for further development of more brief screening instruments for such assessments.

Furthermore, there is a need for follow-up programs aimed to identify and support the subgroup of patients that experience problems after discharge. It can be assumed that such programs would decrease the persistent distress in individuals with severe burns [39].

Due to the wide range of post burn problems experienced by the discharged patients, it is required that assessment and follow-ups will be provided by multidisciplinary teams. In addition, our results suggest that improved information routines may also improve the level of satisfaction with both acute care and aftercare.

Our studies indicate that most patients are satisfied with the hospital care. However, in spite of a serious approach to identify individual and injury-related factors that explain patient satisfaction, only up to 25 % of the variability could be accounted for. This suggests that factors related to care may play a greater role than those factors assessed by us. Approaches to identify which procedures, or moments during the long care period that affect the satisfaction ratings constitute a natural next step.
Conclusions

Half of the former patients who were thought to be at risk for having health problems had contact with healthcare services many years after their burn.

Care utilisation was associated with poorer perceived burn-specific health, higher scores for personality traits related to neuroticism and a lower degree of social desirability. Personality traits were more strongly associated with care utilisation than injury severity.

Former patients with high degree of social desirability displayed significantly poorer perceived health than normal responders with respect to skin- and appearance-related health problems.

Recalled negative experiences during burn care were infrequent. The most common experience recalled was Powerlessness.

A high degree of patient satisfaction was indicated in patients injured 1-6 years previously. The lowest level of satisfaction was noticed for the subscale Adequate treatment information.

Generally, patient satisfaction was more associated with variables indicating interpersonal aspects than with injury-related variables. However, no strong predictors of patient satisfaction were found which suggests that factors related to the care itself may be of greater importance for patient satisfaction than personal factors and trauma-related factors.
Acknowledgements

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A doctoral dissertation from the Faculty of Medicine, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine. (Prior to January, 2005, the series was published under the title “Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine”.)